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Providing knowledge and support to caregivers of older adults: Investigation of two programs

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Providing knowledge and support to caregivers of older adults: Investigation of two programs

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The student author and the program of study committee are solely responsible for the content of this thesis. The Graduate College will ensure this thesis is globally accessible and will not permit alterations after a degree is conferred.

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ABSTRACT

An estimated 34.2 million informal caregivers provided care to adults 50 and older in the United States in 2015. Due to the demands of caregiving, approximately 65% of caregivers report moderate to severe levels of stress. To provide support to caregivers and thereby enhance care provided to care recipients, various programs and long-term services and supports (LTSS) are available. However, many caregivers are unaware or do not have adequate knowledge about these resources. The purpose of this thesis was to analyze knowledge of LTSS and feelings of strain in caregivers by examining two programs aiding in the effort to support caregivers and provide them with resources.

Study 1 explored the Caregiver Beginnings Workshop, which was a one-time educational session aimed at providing caregivers with information regarding available services as well as providing knowledge to assist them with caregiving responsibilities. A block regression was completed to examine predictors of knowledge of LTSS in caregivers. The findings of study 1 included living in a more rural area was a predictor of higher levels of knowledge of LTSS. It was also found that perceived infrequent support was a predictor of lower levels of knowledge of LTSS. County-level indicators were also explored.

Study 2 examined the Health and Resilience Outreach (HERO) program, which was a telephone-based program that recruited volunteers to provide support and service referrals to caregivers. This program aimed at decreasing or maintaining caregiver strain, improving access to services, and enhancing caregiver resiliency. A generalized linear model was analyzed to examine predictors of caregiver strain. The results of study 2 indicated that age, relationship type, initial strain, and changes in care recipient health behaviors were predictors of strain.

Overall, both studies suggest that by increasing the understanding about personal and community level characteristics that impact caregiver knowledge and strain, future efforts

directed towards improving the lives of caregivers will be better informed and more effective. These efforts can help to inform future programs and policies regarding increased support and resources for caregivers because, as these results indicated, providing increased support benefits caregivers and thereby ultimately the care receiver.

CHAPTER I. INTRODUCTION

Family, friends, and other people who provide unpaid care for a loved one are considered informal caregivers (National Alliance for Caregiving and the American Association of Retired Persons, 1997). In 2015, there were an estimated 34.2 million informal caregivers to adults 50 or older in the United States (National Alliance for Caregiving and the American Association of Retired Persons, 2015). Nearly 50% of caregivers provide care to an individual with Alzheimer's disease or a related dementia; therefore, there are more than 15 million informal caregivers for individuals with Alzheimer's disease and related dementias in the United States (Alzheimer's Association, 2017). These caregivers provide an estimated 18.2 billion hours of unpaid care each year and the economic worth of the care they provide is valued at $230.1 billion (Alzheimer's Association, 2017). In Iowa alone, there are 135,000 caregivers who provide an estimated 154 million hours of unpaid care each year, which is valued around $1.9 billion (Alzheimer's Association, 2017).

As the number of care hours per week increases, caregivers can be prone to feelings of burden and stress (Kim, Chang, Rose, & Kim, 2012). Forty percent of caregivers report that they feel their caregiving situation is highly stressful and an additional 25% of caregivers report a moderately stressful caregiving situation (National Alliance for Caregiving and the American Association of Retired Persons, 2015). Springate and Tremont (2014) described caregiver burden as comprised of three main dimensions: impact of caregiving on the caregivers' lives, guilt, and frustration and embarrassment. In their study, depressive symptoms were related to two of the dimensions of caregiver burden, the direct impact of caregiving upon caregivers' lives and guilt (Springate & Tremont, 2014). In other work, caregivers with increased social support from family and friends reported lower levels of burden (Yu, Wang, He, Liang, & Zhou, 2015).

Feelings of burden reported by caregivers can be attributed to a lack of resources and service utilization available to both the person with dementia and to the caregiver. Often caregivers lack awareness and knowledge of resources (e.g., community-based programs, home-based programs, support groups, respite care) that are needed when providing care (Casado, van Vulpen, & Davis, 2011). Living in a rural area versus an urban area may be a factor in the knowledge of available services in the caregiver's area (Morgan, Semchuk, Stewart, & D'Arcy, 2002). Health care providers in rural areas have expressed that they believe caregivers lack information regarding services in the area and the importance of using them, particularly early on in the disease (Morgan et al., 2002).

Knowledge of resources and services is important for caregivers as this information assists caregivers' in their ability to provide both self-care and quality care to the care recipients. Reducing caregiver burden can help to increase the psychological and physiological well-being of the caregiver (McConaghy & Caltabiano, 2005). The reduction in feelings of burden can also help to increase the quality of life of the care recipient. A reduction in burden may keep the care recipient at home longer as caregivers reporting higher levels of burden are more likely to place their care recipients in long-term care (Eska et al., 2013). As caregivers feel more burdened and stressed, they have poorer self-reported health (Son et al., 2007). One reason cited for long-term care placement is the caregiver's declining health (Buhr, Kuchibhatla, & Clipp, 2006) Caregivers who cite their health as a reason for long-term care placement were more likely to have higher stress and lower life satisfaction (Buhr et al., 2006). Caregivers' well-being can be enhanced via interventions and increased social support leading to an overall reduction in long-term care placement of the care recipients (Mittelman, Haley, Clay, & Roth, 2006). Further examination of caregivers' knowledge of various services and resources is needed as well as interventions

targeting reducing levels of burden among caregivers. Such efforts promise to yield improved results for both informal caregivers and their care recipients.

CHAPTER II. LITERATURE REVIEW

Context of Caregiving

Informal caregivers are people who provide care for others who are no longer able to fully care for themselves (National Alliance for Caregiving and the American Association of Retired Persons, 1997). In contrast to formal caregivers, the care that informal caregivers provide is unpaid (National Alliance for Caregiving and the American Association of Retired Persons, 1997). It is important to study informal caregivers as 83% of all care provided to older adults is provided by informal caregivers (Alzheimer's Association, 2017). It is noted that care partner is a regularly used term; however, for the sake of clarity in this paper the terms caregiver and care recipient will be used. However, this is not meant to diminish autonomy of the caregiver or the care recipient.

Caregivers come from a variety of backgrounds and have different stories to tell about their caregiving experience. While some positive outcomes of caregiving are possible, at least 65% of caregivers feel moderate to severe levels of stress due to their caregiving situation and experience (National Alliance for Caregiving and the American Association of Retired Persons, 2015). Kim, Chang, Rose, and Kim (2012) found in caregivers of people with dementia, the person with dementia's functional declines in activities of daily living and instrumental activities of daily living were the most significant predictors of caregiver burden. Other common predictors of burden included living in the same household, increased hours spent caregiving, being a spousal caregiver, and a being female caregiver (Kim et al., 2012). In contrast, higher education and higher income have been related to lower feelings of burden in caregivers (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). As can be seen, caregiver

feelings of burden can vary due to personal characteristics, however the care recipient's type of disease may affect caregiver burden as well.

Type of Disease

Feelings of burden experienced by the caregiver can vary by the specific disease of the care recipient. Caregivers of people with dementia tend to feel burdened due to disease-related factors including care recipients' functional impairments of activities of daily living and instrumental activities of daily living (Kim, Chang, Rose, & Kim, 2012). Similar to caregivers of people with dementia, predictors of burden in caregivers of people with Parkinson's disease include disease-related factors, such as severity of the disease (Martínez-Martín et al., 2007), as well as feeling socially isolated (Roland, Jenkins, & Johnson, 2010). Jaracz et al. (2015) found that caregivers of people who experienced a stroke tend to feel most burdened due to anxiety and length of time caregiving. Thommessen et al. (2002) found that three groups of spousal caregivers, those caring for people with dementia, stroke, and Parkinson's disease, had similar perceived psychosocial burden, often reporting problems due to disruptions in household routines, less time for their own social lives, and sleep disturbances. However, they found that only the caregivers for the individual's with Parkinson's disease and stroke had higher psychosocial burden due to reduced cognitive function in the care recipient (Thommessen, et al., 2002). Therefore, creators of interventions and programs targeting caregivers should keep in mind the potential differences caregivers experience due to their caregiving situation.

Relationship Type

Among informal caregivers, approximately 42% are providing care for their parents (National Alliance for Caregiving and the American Association of Retired Persons, 2015). Women comprise two-thirds of informal caregivers and, more specifically, daughters represent

over one-third of informal caregivers for individuals with Alzheimer's disease and related dementias (Alzheimer's Association, 2017). Pillemer and Suitor (2013) found that among adult-children, daughters were almost twice as likely as sons to become caregivers. Adult child caregivers have multiple other roles in their lives other than that of being a caregiver. One main role many adult children have is being a parent. Many adult children are in the "sandwich generation," which means they are responsible for caring for their own children and also their parents (Hammer & Neal, 2008). As such, these caregivers are placed between two generations like pieces of bread in a sandwich and must manage caring for people in two different stages of life. Adding to potential stress and burden is the fact that more than one half of adult child caregivers are employed (Johnson & Wiener, 2006).

Following adult children, spouses or partners are the most frequent informal caregiver for persons aged 65 and older (National Alliance for Caregiving and the American Association of Retired Persons, 2015). Approximately 20% of informal caregivers are 65 or older (National Alliance for Caregiving and the American Association of Retired Persons, 2015) and many also have health problems of their own while providing care to their loved one (Johnson & Wiener, 2006). Spousal caregivers that had been in a parenting role oftentimes find this role changes as they age due to the fact that their children move out and begin to have families of their own (Lima, Allen, Goldscheider, & Intrator, 2008). Older spousal caregivers may become grandparents and must learn how to balance their role as a grandparent while continuing to provide care for their loved one (Lima et al., 2008). Spousal caregivers are less likely to be employed full-time and more likely to be retired or working part-time (Pinquart & Sörensen, 2011).

Caregiver Burden and Long-term Services and Supports

As caregivers continue to provide care, they may begin to have experiences that affect the care they are providing to the care recipient. An increase in feelings of burden may begin to interfere with the quality and the duration of care that caregivers provide their loved ones (McConaghy & Caltabiano, 2005). Also, increased physical and mental health issues, such as depression, experienced by the caregiver may interfere with the quality of care they provide (Beach et al., 2005). Programs and services are available for caregivers that allow them to take time for themselves and step away from their caregiving responsibilities for a short time, such as respite or in-home health care. These services facilitate caregivers' abilities to continue to provide quality care to their loved one while also taking care of themselves (Pinquart & Sörensen, 2006).

It is also beneficial to care recipients to continue to connect to their communities (Phinney, Chaudhury, & O'Connor, 2007). Many people with dementia enjoy being able to be connected to their church or to other community programs (Phinney et al., 2007). Many care recipients benefit from attending adult day services and as a result tend to show a decrease in behavioral problems (Gaugler et al., 2003). Caregivers also benefit as they report lower levels of care-related stress and more positive experiences during times when care recipients attend adult day services (Zarit, Kim, Femia, Almeida, & Klein, 2013). As a way for caregivers and care recipients to receive benefits and reduce stress, different options of long-term services and supports are available.

Long-term services and supports (LTSS) consist of "a broad spectrum of options for people who – because of ongoing disabilities and chronic conditions – require long-term assistance, delivered in settings that range from private residences to assisted living facilities and

nursing homes" (Reinhard, Kassner, & Houser, 2011, p. 448). Taking advantage of available LTSS is important for caregiving to be optimized; however, many caregivers do not have knowledge of the services or have awareness of the services (Casado, van Vulpen, & Davis, 2011; Strain & Blandford, 2002). For the purposes of this study, knowledge of LTSS is the understanding of what the service is and what it provides to the care recipient and the caregiver. Awareness of LTSS is the understanding if the service is available in the area and for whom it is accessible. Having knowledge and awareness of LTSS predicts the use of LTSS (Tang & Pickard, 2008). In-home LTSS use by caregivers has been shown to delay long-term care placement (Gaugler, Kane, Kane, & Newcomer, 2005).

Theoretical Perspectives

Two theories were utilized to understand the context of caregiving. First, Bandura's self-efficacy theory was used to understand the context in which caregivers' knowledge of LTSS is an important step in becoming more confident in their capabilities to accomplish a task in their caregiving duties (Bandura, 1982). Then, the bioecological theory was used to understand different levels of support that surround caregivers and interactions that happen within these levels (Klein et al., 2015; Tudge et al., 2009). Together, these two theories complement each other and help to gain a broader understanding of how caregivers gain knowledge and support while caregiving but also how surrounding interactions with others and society effect their caregiving.

Study Purpose

In general, caregivers spend approximately four years in their caregiving role; however, caregivers who spend 21 or more hours providing care per week are twice as likely to spend 10 or more years in their caregiving role (National Alliance for Caregiving and the American

Association of Retired Persons, 2015). Approximately one-half of caregivers report caring for a loved one with Alzheimer's disease or a related dementia (Alzheimer's Association, 2017). This number is only going to grow in the coming years. In the United States, approximately 14% of individuals 71 years and older have a form of dementia (Plassman et al., 2007); this includes 5.5 million people who are specifically diagnosed with Alzheimer's disease (Alzheimer's Association, 2017). In the coming years, there will be a considerable increase in the number of people with Alzheimer's disease and other related dementias to an estimated 13.8 million people age 65+ by 2050. (Hebert, Weuve, Scherr, & Evans, 2013). There is a need to find out more about how to support caregivers thereby supporting people with dementia. To aid this effort, this thesis offers an opportunity to look at two programs created to assist informal caregivers. A two-paper approach is used. In the first paper, we examined an early caregiver educational program developed to enhance knowledge of LTSS. The knowledge caregivers have about long-term services and supports and the characteristics caregivers with more knowledge of LTSS are likely to have was analyzed. Within the second paper we investigated a volunteer program also designed to provide support as well as referral and education about LTSS. In addition, we examined caregivers in the context of programs as these programs should help enhance caregivers' self-efficacy and overall help them to manage their caregiving responsibilities as well as increase their access to services and supports. The dosing of a program, how many times the volunteer contacted the caregiver, was examined to see how that affects the caregivers' feelings of burden. For both programs, caregiver relationships were explored.

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CHAPTER III. CAREGIVER KNOWLEDGE OF LONG-TERM SERVICES AND SUPPORTS: EFFECTS OF RURALITY AND SUPPORT

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Literature Review

Informal caregivers have a challenge facing them as they learn to care for their loved one's physical, behavioral (e.g., agitation, wandering), and emotional needs. Unfortunately, caregivers of people with dementia often lack knowledge about dementia (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011) as well as knowledge and awareness of available long-term supports and services (LTSS) that can enhance care provided to the care recipient (Casado, van Vulpen, & Davis, 2011).

Several important factors such as availability of the service, level of need, and presence of a physical disability can affect knowledge and use of LTSS (Brodaty, Thomson, Thompson, & Fine, 2005). Older caregivers are less likely to know about the availability of services (Collins, Stommel, Given, & King, 1991). Caregivers with knowledge on where to obtain information regarding community services are more likely to have support from their physicians and home health services (Ploeg et al., 2009). Caregivers with higher levels of education tend to know more about the available services (Collins et al., 1991). Specific to spousal caregivers, Werner (2001) also found that caregivers with lower education were more likely to have lower LTSS knowledge. Unfortunately, prior work also suggests that spousal caregivers are also less likely to use community resources (Robinson, Buckwalter, & Reed, 2005). Caregivers experiencing

depression are less likely to know about the availability of services, and the more depressed the caregiver is, the less likely that caregiver is to know if the service is available (Collins et al., 1991).

To help caregivers understand and gain knowledge about their caregiving role and responsibilities, there are various programs available to caregivers that vary on target audience, delivery method, and intervention objective. Many of the programs focus exclusively on caregivers of persons with dementia whereas other programs are available to all caregivers. Programs can be offered in-person, in a group setting or an educational setting, or they can also be offered on the phone or through online educational programs. The majority of programs focus on managing caregiver burden and self-care. Fewer programs focus on early-stage caregivers or increasing knowledge of long-term services and supports. Table 1 provides an overview of interventions available to caregivers and what they offer.

There are programs available that are aimed at increasing caregiver knowledge on a variety of topics, including knowledge of services (Benjamin Rose Institute, 2016; Ducharme et al., 2011; Smith & Toseland, 2006). In regard to self-care, Powerful Tools for Caregivers is a national program that is offered to informal caregivers and directs its efforts to providing caregivers with “tools” to care for themselves, such as communication skills, self-care behaviors, and managing and improving emotions (Boise, Congleton, & Shannon, 2005). Another program, Learning to Become a Family Caregiver, focuses on creating a positive transition into the caregiver role, allowing the caregiver to feel more prepared as they step into this role, and helping them acquire skills to adapt to their new role (Ducharme et al., 2011). Another type of intervention focuses on caregiver knowledge of the care recipient’s disease. For example, SHARE (Support, Health, Activities, Resources, and Education: The SHARE Program for Early-

Stage Families) is a program in which caregivers learn more about symptoms of dementia and prepare for future care of the care recipient (Benjamin Rose Institute, 2016). There are also more programs becoming available through technology to make them more accessible to caregivers. The Telephone Support Groups are sessions over the phone with a licensed social worker and other caregivers to provide the caregivers with education about chronic illnesses and resources along with strategies for coping and problem-solving (Smith & Toseland, 2006).

Unfortunately, caregivers may experience several barriers when accessing programs and resources in their communities. For instance, rurality can create a problem in accessing programs and resources for caregivers (Brodaty, Thomson, Thompson, & Fine, 2005). Rural versus urban location and transportation availability are predictors of service use (Toseland, McCallion, Gerber, & Banks, 2002). Living in a rural area can create a barrier to the use and knowledge of services and resources due to the distance of travel to services, lack of transportation, and the limited availability of services (Morgan, Semchuk, Stewart, & D'Arcy, 2002). Overall, caregivers living in rural areas may have a difficult time obtaining knowledge and accessing available services and programs.

Theoretical Perspective

Knowledge about long-term services and supports is needed for caregivers to be successful at providing care to their loved one. Self-efficacy is defined as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (Bandura, 1994, p. 71). So, to fully accomplish a task, such as caregiving, there needs to be more than knowledge to complete it successfully (Bandura, 1982). The belief people have in their own abilities to complete a task enhances their well-being as well as the ability to finish the task (Bandura, 1994). However, individuals who do not believe in their

abilities will not put as much effort into completing the task (Bandura, 1982). Thereby, interventions and programs are available to caregivers to increase knowledge as well as self-efficacy in caregiving responsibilities.

Study Rationale

Caregivers often underutilize or are unaware of services in their surrounding area that will benefit them and their care recipients (Casado, van Vulpen, & Davis, 2011; Strain & Blandford, 2002). This lack of knowledge and awareness may cause an increase in caregiver feelings of burden because they must take on more care responsibilities as they have no services to rely on to help them. The Caregiver Beginnings Workshop was aimed at providing new caregivers with this information and giving them the needed knowledge in the early stages of caregiving (Seedorf, 2014).

We investigated caregivers' knowledge of LTSS to find identifying features of what type of caregiver is likely to be more or less knowledgeable about LTSS. The aim of this study was to identify at-risk caregivers that have less knowledge of services. Future programs and interventions can then provide information about LTSS and be aware of the caregivers that may need extra information regarding LTSS.

Research Questions

For this study, the first research question was what are caregiver predictors of knowledge of LTSS among caregivers? I hypothesized that caregivers endorsing greater perceived support and those with higher educational attainment would have more knowledge about LTSS. The second research question was what are care recipient predictors of knowledge of LTSS in caregivers? I hypothesized that caregivers of people with more than one illness would have more knowledge about LTSS. The third research question was what are dyadic-level predictors of

knowledge of LTSS in caregivers? I hypothesized that adult child caregivers would have more knowledge about LTSS compared to spouses/partners and other types of relationships. The final research question was what are the context predictors of knowledge of LTSS in caregivers? I hypothesized that those living in more populated areas would have more knowledge about LTSS.

Method

Design and procedure

The Caregiver Beginnings Workshop was designed to be a one-time educational session for caregivers and lasted approximately two hours and 15 minutes. Caregivers for people with all diseases and disabilities were invited to participate in the workshop. The participants took a pretest before the beginning of the workshop and a posttest after the completion of the workshop. There was an additional 15 minutes at the beginning and the end of the workshop to accommodate the pretest and posttest. Demographic information, a scale to measure caregiver knowledge and awareness of LTSS, and a scale to measure caregiver feelings of preparedness were included on the pretest and posttest.

The Caregiver Beginnings Workshop was created to assist caregivers in addressing their care-related concerns, locate community services and resources, and create a care plan (Seedorf, 2014). The workshop was designed to be collaborative so that caregivers could interact with each other and ask questions or make suggestions. A facilitator provided information on common caregiver concerns as well as community resources and services. Each item from a list of 26 long-term services and supports (LTSS) was discussed and reviewed. Caregivers then had the opportunity to learn about care plans and discuss typical caregiving scenarios and design care plans for those scenarios. Lastly, the facilitator led a discussion about caregiver burden, the impact burden can have on the caregiving situation, and where to find support and resources.

Throughout the workshop caregivers had the opportunity to ask questions. The workshop was held in 2013-2014 at 12 locations in 11 counties throughout Iowa. Community and faith-based organizations that serve or have members who are caregivers were invited to host the workshop. Organizations that became hosts of the workshops were asked to provide a list of LTSS in the surrounding area and, if the list was provided, it was distributed to the participants during the workshop.

Participants

Host organizations received advertising materials for the workshop to recruit participants. Workshops had a range of three to 14 participants. The original intent of the workshop was to reach non-spousal caregivers who had been caregiving for a year or less. However, there was a greater variety of participants than expected and everyone who was recruited and participated in the workshop was included in the sample.

A total of 98 caregivers participated in the sessions; however, only 90 caregivers were included in the analyses due to missingness. Seventy-one of the participants were female (19 male). The average age of the participants was 61 years (*SD* = 11.1, *Range* 22-84). Eighty-eight participants were White, one participant reported a multi-ethnic background, and one participant was Asian American. Thirty-nine participants were adult child caregivers, 12 were spouses or partners, and 29 were other caregivers (e.g., sibling, grandchild). One participant had less than high school education, 18 had a high school education, 24 had technical, trade, or vocational training, 28 had a four-year degree, and 19 had a graduate degree. See Table 2 for participant demographics.

Measures

Caregiver knowledge of LTSS was assessed by using The Knowledge of Long-term Services and Supports Scale (Toseland, Rossiter, Peak, & Smith, 1990). This is a 26-item scale used to measure the knowledge caregivers have of different services (e.g., adult day center, home delivered meals, respite care). The reliability of this The Knowledge of Long-term Services and Supports Scale within this study was a Cronbach's alpha of .91. The question asked on this scale was "Do you know what this service is?" The response categories were "Yes" or "No". Table 3 shows the frequency at which participants answered yes or no for each of the 26 items. A total score was created by summing each of the 26 items of the scale with zero as the lowest score possible and 26 as the highest score possible.

Initially, 26 participant reports (27%) reflected some degree of missingness. To address the missing, patterns were examined for the participants with missing data to see if there was a possibility for data imputation. Three patterns emerged. First, for 14 participants with one to five items missing, a mean score of their remaining items was substituted for missing items. Second, three participants who first began by answering yes/no and then switched to answering yes/missing had their missing items changed to no. Lastly, one participant who answered yes/missing had their missing items changed to no. Reports for eight participants remain missing, as they possessed a high percentage of missing items with no way to infer intent. Table 2 depicts the demographics of the sample of the participants for whom missing items were imputed and the 72 participants who had fully reported the knowledge items.

The remaining demographic questions were single item questions on the survey. Caregiver education was measured by the question "What is the highest level of education you completed?" The response categories for this question were "__ Grade", "HS Graduate or GED",

“Technical or Trade or Vocational training”, “Four year degree”, or “Graduate degree”. This variable had no missingness.

Caregiver relationship was measured using the question “What is your relationship to the care recipient?” The response categories included “Child”, “Spouse or Partner”, “Grandchild”, Niece or Nephew”, “Sibling”, “Neighbor”, and “Other, please define”. Based on theory and theoretical distinctiveness, “Child” and “Spouse or Partner” remained the same, but the other five response categories were collapsed into one “Other” category, thereby creating three overall categories. Child was used as the reference group. This item had 12% missingness.

Caregiver support was measured via the question “How much support do you feel in your caregiver role?” The response categories for this were “Very supported”, “Somewhat supported”, “Rarely supported”, and “Not supported at all”. “Very supported” and Somewhat supported” remained the same, but the final two categories were combined to create on “Infrequent or No Support category”, thereby creating three overall categories. Very supported was used as the reference group. This item had 37% missingness.

Care recipient illness was measured using a single question “What condition or illness is the care recipient suffering from, if any?” This was an open-ended question, but did provide examples (i.e., Alzheimer’s disease/dementia, cancer, congestive heart failure, COPD, diabetes, Parkinson’s disease, stroke, other). Caregivers could indicate more than one illness when answering this question. Based on the examples provided, a total out of seven was created for this variable. The other category was not used in this total. This variable had 23% missingness.

Rurality was assessed using caregiver zip code. There were 15 different counties in total. Then, the counties were separated into categories using the Rural-Urban Continuum Codes (United States Department of Agriculture: Economic Research, 2013). The counties fell under

seven of the nine rurality codes, higher codes are indicative of greater rurality. If a zip code was separated between two counties, the county in which the workshop was held was chosen. This affected 20 participants. This variable had no missingness. Information regarding measures is provided in Table 2.

Analytic plan

To understand the caregiver, care recipient, dyadic, and context predictors of knowledge of LTSS, a block regression was conducted to identify predictors of LTSS knowledge according to different groups of theoretically similar characteristics. The first block contained caregiver characteristics (i.e., education and reported social support). The second block included a care recipient characteristic, number of care recipient illnesses. The third block included a dyadic predictor, relationship type. The fourth block focused on context and consisted of rurality as a predictor. Exploratory descriptive analyses, such as chi-squares, were run to examine knowledge by certain predictive variables. Overall, this approach described predictors of knowledge of LTSS among caregivers of older adults.

Results

Chi-square tests were conducted to investigate potential differences between the groups of participants who had some missing and no missing data. One significant difference was found reflecting a difference between the groups in the degree of perceived support, χ^2 (2, N = 59) = 7.01, p = .03. The difference between these groups suggests that participants who had some missing data were more likely to report feelings of being somewhat supported. However, after consideration of this difference, these participants were included in the final analyses.

Ninety participants were included in the analyses. The mean score on the Knowledge of LTSS Scale was 17. A Pearson product-moment correlation was estimated to analyze the

association among five primary variables, excluding relationship type (see Table 4). Rurality was significantly associated with total care recipient illness as well as with caregiver knowledge of LTSS.

Bivariate regressions were employed to understand the separate relationships between each independent variable and the dependent variable. After results of the bivariate regressions were examined, a block regression analysis was conducted to help understand the utility of all predictors (i.e., caregiver characteristics, care recipient characteristics, dyadic characteristics, or rurality) in predicting caregiver knowledge of LTSS together (see Table 5). The first block tested the relationship between caregiver education and caregiver support. Caregiver support was represented by two categories of caregivers who felt somewhat supported and caregivers who felt infrequent or no support (reference group was caregivers who felt very supported). The results indicated that these predictors did not account for a significant proportion of the explained variance in caregiver knowledge of LTSS (R^2 = .07). The second block included the variable total number of care recipient illnesses. This combined effect of the first two blocks was also not significant (R^2 = .07, ΔR^2 = .00). Block three included relationship type which was represented by two categories: spouse and other relationship types (adult child was the reference group). Again, neither of these predictors were significant and the combined set of predictors accounted for a small amount of the explained variance (R^2 = .11, ΔR^2 = .04). The final block included rurality along with the other predictors. Rurality (B = 0.98, β = 0.33, p = .047) along with infrequent or no support (B = -4.67, β = -0.30, p = 0.02) were significant predictors, with the complete model accounting for 21% of the explained variance (R^2 = .21, ΔR^2 = .10). These findings indicate that caregivers living in rural areas reported higher knowledge of LTSS. In contrast, caregivers who reported infrequent or no support also indicated less knowledge of

LTSS. It should be noted that when the final regression model was estimated without the 18 participants who had data imputed, then infrequent support was no longer significant.

To further understand the relationships between caregiver knowledge of LTSS, rurality, and caregiver support, chi-square statistics and crosstabulations were examined. However, the chi-square results were not significant for these variables. Examination of the crosstabs reinforced the results found in the regression: that caregivers living in more rural areas (see Table 6) and caregivers who felt very supported (see Table 7) were more likely to have higher levels of knowledge of LTSS. Table 8 displays the relationship between rurality and caregiver feelings of support. This relationship suggests that caregivers living in the most urban area (USDA code 2) were more likely to report that they felt very supported compared to caregivers living in less urban and more rural areas (USDA codes 3-7). However, those who lived in the most rural area (USDA code 9) were more likely to report they feel very supported or they feel somewhat supported.

As rurality was a significant predictor of knowledge of LTSS, further exploration was conducted on a county-level to better understand community resources. Nationally available data through the Centers for Disease Control, Medicare, and the United States Census were compiled to identify “care deserts” located throughout Iowa for the Care Deserts Project (University of Iowa Prevention Research Center for Rural Health, 2015). Using county-level indicators identified in this project, Table 9 depicts 10 indicators, including the USDA urban-rural continuum codes (United States Department of Agriculture: Economic Research, 2013), for each of the 15 counties represented in the Caregiver Beginnings Workshop believed to exert county-level influence on caregivers’ knowledge of LTSS. Table 10 shows the correlation matrix for these variables. These variables were then included in bivariate regressions with knowledge of

LTSS. The results indicate that median income (B = 0.00, β = -0.32, p = 0.002, R^2 = *.11*) and an educational attainment of an associates level degree or higher (B = -0.16, β = -0.30, p = 0.004, R^2 =*.09*) were significant in bivariate regressions of knowledge of LTSS. However, when the county-level variables were included in a block regression including the independent variables from the Caregiver Beginnings Workshop data, these variables were no longer significant predictors.

Discussion

The purpose of this study was to investigate caregivers' knowledge of LTSS and to identify characteristics predictive of caregiver knowledge. Findings indicated that perceived inadequate support was a predictor of lower knowledge of LTSS in this sample of caregivers and living in rural areas was a predictor of higher knowledge of LTSS. Overall, this study aimed to identify the characteristics of at-risk caregivers who have less knowledge of available services thereby informing future programs and interventions of caregivers that may need extra information regarding resources and help accessing LTSS.

Regarding rurality, caregivers residing in more rural areas reported higher levels of LTSS knowledge. This finding that caregivers living in more rural areas are more likely to have a higher knowledge of LTSS was contrary to my hypothesis. One potential reason for caregivers who reside in more rural areas reporting higher levels of knowledge of LTSS is that they become aware and knowledgeable of the offered services within their community. They may have fewer services available because they live in more rural areas, but the caregiver in those circumstances may realize a need to become more familiar with the services. They may also have more local services, such as programs provided through churches or community centers, which they utilize on a more regular basis.

Another potential reason of higher knowledge in rural areas is that the care recipient may stay at home longer and the caregiver may provide care for them longer in a more rural area thereby creating more time for them to know about available services. Lastly, living in a close-knit community that many rural areas have may contribute to higher knowledge of LTSS. Creating and maintaining close relationships with other people in the community would allow for information of services to be exchanged and for help to be given when needed. This greater sense of support throughout the community could lead to higher knowledge of LTSS.

The findings in this study show that caregivers reporting infrequent or no support had less knowledge of LTSS. This supports the idea that residing in a close-knit community would create a sense of support for the caregiver, thus producing higher levels of LTSS knowledge. However, the county-level indicator of inadequate social support was analyzed but was not a significant predictor of knowledge of LTSS. Though, this variable contained missing data in the more rural counties, indicating that perhaps there is information missing from these counties about their levels of support. Overall, caregivers experiencing inadequate support is a problem that needs to be addressed. As indicated in the post-hoc analyses, however, caregivers from both urban and rural areas reported inadequate support; thus, more support needs to be provided to caregivers in all areas. Support can be provided in informal ways, through family and friends. It can also be provided through formal ways such as through organizations, programs, and services. These formal services need to ensure they are reaching caregivers in all areas, both urban and rural. Some caregivers may also be hard to reach and may find it hard to leave their care recipients due to their caregiving responsibilities; therefore, there needs to be a way to reach these harder to reach caregivers and support them while they are caregiving for their loved ones.

Examination of the analyses revealed that personal characteristics, other than infrequent support, were not predictors of knowledge of LTSS; however, county-level characteristics, such as rurality, median income, and education level were significant predictors of knowledge. The data in the current study did not fully capture knowledge of LTSS on a personal-level, but there was an aspect to the county-level data that was apparent that affected the knowledge caregivers had on LTSS. The county-level data that were examined provided an insight into the context that surrounds the caregiver while they are providing care to their loved ones. The context surrounding the caregiver proved to have an important impact on the knowledge of LTSS a caregiver has. County-level income and education were predictors of knowledge of LTSS; however, this finding indicated that counties with a lower level of income and lower levels of education are more likely to have higher knowledge of LTSS. This finding is likely due to the fact that in this sample, the rural counties have lower levels of income and education, as can be seen in Table 9, and rural counties are more likely to have higher levels of knowledge of LTSS. Further research is needed to adequately capture the county-level influences that were not addressed by personal characteristics of the caregivers.

Limitations and future directions

There were limitations to this study. The first limitation was the amount of missingness that was present throughout the majority of the variables used in this study. Data were imputed to account for the missing; however, a significant difference was found between the group of participants with complete data and the group of participants who had data imputed. A second limitation was the sample size, which likely resulted in an underpowered model. Another limitation was that the Knowledge of Long-term Services and Supports Scale was not a robust measure as it only had the response categories of yes or no and was self-reported.

The effect rurality has on knowledge of LTSS needs to be further understood and researched. Future research should examine the services and resources that are available in each area or county that the caregivers live in and how caregivers access those services and compare that to the level of knowledge the caregiver possesses. This will give an insight into how the available services influence the caregiver's level of knowledge.

Future research should also focus on the effects of support in caregivers' lives. Differing levels of support affect their knowledge of LTSS and this needs to be understood more fully. Potential future directions for this line of research could analyze support using a more robust measure as well as understand the caregivers' support system. Also, programs need to identify caregivers who feel they have little support and provide ways to support them.

Future programs and interventions should note at-risk caregivers who may have less knowledge of LTSS include caregivers with feelings of inadequate support. Programs should target caregivers who have infrequent support and provide support as well as information regarding available resources. As indicated by this sample, rural communities may provide some advantages for caregivers; however, programs need to be aware increasing knowledge is an issue for all caregivers. This includes caregivers in more urban areas who may not be as knowledgeable about services and supports and may need extra information about LTSS in their surrounding areas.

Conclusion

Due to their positive effects on both the caregiver and care recipient, improving knowledge of LTSS is critical to decreasing care strain and costs, which ultimately would enhance the quality of life for older persons and their caregivers. Unfortunately, caregivers often lack knowledge of available services, which indicates that future efforts should examine why

caregivers may lack knowledge and discover ways to help them gain knowledge about community services. Based on the results of this study, it is also important to examine the various characteristics that may be affecting caregivers and their knowledge of services, such as the personal and community level constraints. Understanding these aspects can help to inform future programs and, eventually, policy implementation regarding support and resources for caregivers. Identifying at-risk caregivers is important to be able to find ways to target programs and interventions to help them better navigate their caregiving responsibilities.

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Table 1. Extant Caregiver Interventions

Intervention	Target Audience		Delivery		Intervention Objective	
	Care Recipient Condition	Early-Stage	In-Person	Telephone/ Computer	Burden/ Self-Care	Increase LTSS Knowledge
Powerful Tools for Caregivers[1]	All Caregivers		X		X	
TSG[2]	All Caregivers			X	X	X
Caregiver Beginnings Workshop[3]	All Caregivers	X	X			X
SHARE[4]	Alzheimer's/Dementia Caregivers	X	X		X	X
EPIC[5]	Alzheimer's/Dementia Caregivers	X	X		X	
REACH[6]	Alzheimer's/Dementia Caregivers		X	X	X	
Learning to Become a Family Caregiver[7]	Alzheimer's/Dementia Caregivers	X	X		X	X
FITT-D[8]	Alzheimer's/Dementia Caregivers			X	X	
HERO[9]	Alzheimer's/Dementia Caregivers			X	X	X

Note. Table adapted from Seedorf (2014). LTSS = Long-term services and supports. [1]The Power Tools for Caregivers intervention is from Boise et al. (2005); [2]Telephone Support Groups (TSG) intervention is from Smith & Toseland (2006); [3]Caregiver Beginnings Workshop is from Seedorf (2014); [4]Support, Health, Activities, Resources, and Education: The SHARE Program for Early-Stage Families intervention is from Benjamin Rose Institute (2016); [5]The Early-Stage Partners In Care: The EPIC project is from the Alzheimer's Association (2017); [6]Resources for Enhancing Alzheimer's Caregiver Health (REACH) program is from Eisdorfer et al. (2003); [7]Learning to Become a Family Caregiver intervention is from Ducharme et al. (2011); [8]Family Intervention: Telephone Tracking – Dementia (FITT-D) is from Tremont et al. (2008); [9]Health and Resilience Outreach (HERO) is from Iowa Department on Aging (2014) and Telligen Community Initiative (2015).

Table 2. Demographics of Participants including Participants with and without Missing Data

	All Participants (N = 90)		Participants with Some Missing Data (n = 18)		Participants with No Missing Data (n = 72)	
	M (*SD*)	*Range*	*M* (*SD*)	*Range*	*M* (*SD*)	*Range*
Age	60.8 (*11.1*)	22-84	62.8 (*9.4*)	50-83	60.3(*11.5*)	22-84
LTSS Knowledge Total[1]	17.0 (6.1)	0-26	17.4 (5.5)	5-26	16.8 (6.3)	0-26
	Frequency	%	Frequency	%	Frequency	%
Sex						
Female	71	78.9	14	77.8	57	79.2
Male	19	21.1	4	22.2	15	20.8
Race						
White/Caucasian	88	97.8	18	100.0	70	97.2
Black/African American	1	1.1	0	0	1	1.4
Asian American	1	1.1	0	0	1	1.4
Education						
Less than High School	1	1.1	0	0	1	1.4
High School or GED	18	20.0	6	33.3	12	16.7
Tech./Trade/Vocational	24	26.7	1	5.6	23	31.9
Four Year Degree	28	31.1	6	33.3	22	30.6
Graduate Degree	19	21.1	5	27.8	14	19.4
Type of Relationship*						
Child	39	43.3	8	44.4	31	43.1
Spouse or Partner	12	13.3	3	16.7	9	12.5
Other	29	32.2	4	22.2	25	34.7
Support*						
Very Supported	20	22.2	1	5.6	19	26.4
Somewhat Supported	25	27.8	9	50.0	16	22.2
Infrequent/No Support	14	15.6	2	11.1	12	16.7
Care Recipient Illness*						
0	20	22.2	5	27.8	15	20.8
1	34	37.8	5	27.8	29	40.3
2	14	15.6	3	16.7	11	15.3
3	3	3.3	1	5.6	2	2.8
USDA Rural-Urban Continuum Codes[2]						
2	25	27.8	4	22.2	21	29.2
3	12	13.3	1	5.6	11	15.3
4	10	11.1	2	11.1	8	11.1
6	28	31.1	8	44.4	20	27.8
7	10	11.1	2	11.1	8	11.1
8	1	1.1	0	0	1	1.4
9	4	4.4	1	5.6	3	4.2

Note. LTSS=Long-term services and supports. GED=General Education Development. USDA= United States Department of Agriculture. [1]Knowledge of Long-term Services and Supports Scale is adapted from Toseland et al. (1990); [2]USDA Rural-Urban Continuum Codes are from United States Department of Agriculture: Economic Research (2013), 2=Metro – Counties in metro

Table 2 continued

Note continued. areas of 250,000-1 million pop., 3=Metro – Counties in metro areas of fewer than 250,000 pop., 4=Non-metro – Urban pop. of 20,000 or more, adjacent to a metro, 6=Non-metro – Urban pop. of 2,500-19,999, adjacent to a metro, 7=Non-metro – Urban pop. of 2,500-19,999, not adjacent to a metro, 8=Non-metro – Completely rural or < 2,500 urban pop., adjacent to metro, 9=Non-metro – Completely rural or < 2,500 urban pop., not adjacent to metro;
*Percentages do not add up to 100% due to missing data.

Table 3. Knowledge of Long-term Services and Supports Scale Items (*n* = 90)

Item	Percentage		
	Yes	No	Missing
Consumer Directed Attendant Care	14.3	77.6	8.2
Case Management – Private	27.6	65.3	7.1
Case Management – Public	29.6	63.3	7.1
Continuing Care Community	34.7	58.2	7.1
Bill Payer	41.8	52.0	6.1
Information and Referral	42.8	49.0	8.2
Remote Electronic Monitoring	44.9	46.9	8.2
Medication Aide	47.9	43.9	8.2
Personal Care Services	48.0	43.9	8.2
Financial Management	54.0	37.7	8.2
Chore Services	55.1	38.8	6.1
Nutrition Counseling	62.2	29.6	8.2
Counseling/Emotional Support	64.3	27.5	8.2
Homemaker Services	64.3	27.6	8.2
Legal Assistance	64.3	29.6	6.1
Errands and Shopping	65.3	27.6	7.1
Respite Care	66.3	25.5	8.2
Personal Emergency Response Device	75.5	16.3	8.2
Transportation	75.5	16.3	8.2
Adult Day Center	77.6	15.3	7.1
Nursing Care – In Home	77.6	14.3	8.2
Home Health Aide	86.7	6.1	7.1
Home Delivered Meals	86.7	5.1	8.2
Nursing care – Skilled Care	86.7	6.1	7.1
Nursing Care – Facility	88.8	4.1	7.1
Assisted Living Facility	92.9	2.0	5.1

Note. For participants that had a missing value filled in with their mean score, scores of .51 and above were included in the yes category and scores of .50 and below were included in the no category. Knowledge of Long-term Services and Supports Scale is adapted from Toseland et al. (1990).

Table 4. Correlation between Characteristics of Caregiving Dyad

Variables	1	2	3	4
1. Caregiver Knowledge of Long-term Services and Supports				
2. Caregiver Education	0.15 *n*=90			
3. Caregiver Support	0.24^{t} *n*=59	-0.09 *n*=59		
4. Care Recipient Illnesses[1]	0.09 *n*=71	-0.03 *n*=71	0.08 *n*=57	
5. Rurality[2]	0.25* *n*=90	0.03 *n*=90	-0.07 *n*=59	0.24* *n*=71

Note. [1]Total number of care recipient illnesses was identified by the caregiver with a range of zero to seven illnesses including Alzheimer's disease/dementia, cancer, congestive heart failure, COPD, diabetes, Parkinson's disease, and stroke; [2]USDA Rural-Urban Continuum Codes are from United States Department of Agriculture: Economic Research (2013), 2=Metro – Counties in metro areas of 250,000-1 million pop., 3=Metro – Counties in metro areas of fewer than 250,000 pop., 4=Non-metro – Urban pop. of 20,000 or more, adjacent to a metro, 6=Non-metro – Urban pop. of 2,500-19,999, adjacent to a metro, 7=Non-metro – Urban pop. of 2,500-19,999, not adjacent to a metro, 8=Non-metro – Completely rural or < 2,500 urban pop., adjacent to metro, 9=Non-metro – Completely rural or < 2,500 urban pop., not adjacent to metro; $^{t}p<.10$. *$p<.05$.

Table 5. Hierarchical Regression Investigating Knowledge of Long-term Services and Supports in Relation to Education, Support, Care Recipient Illness, Relationship Type, and Rurality (n = 57)

Predictor	*B*	*SE*	*β*	Adjusted R^2	R^2	ΔR^2	*p*
Block 1				.02	.07		.28
Caregiver Education	0.29	0.81	0.05				
Caregiver Somewhat Supported	-0.86	1.94	-0.07				
Caregiver Infrequent or No Support	-4.27	2.22	-0.30				
Block 2				.00	.07	.00	.71
Caregiver Education	0.21	0.85	0.04				
Caregiver Somewhat Supported	-1.00	1.99	-0.08				
Caregiver Infrequent or No Support	-4.30	2.24	-0.29				
Total Care Recipient Illness	-0.44	1.17	-0.05				
Block 3				.01	.11	.04	.31
Caregiver Education	-0.06	0.86	-0.01				
Caregiver Somewhat Supported	-0.98	1.99	-0.08				
Caregiver Infrequent or No Support	-3.88	2.25	-0.26				
Total Care Recipient Illness	-0.47	1.21	-0.06				
Spouse Relationship Type	-2.77	2.44	-0.17				
Other Relationship Type	1.23	2.00	0.09				
Block 4				.10	.21	.10	.02
Caregiver Education	-0.08	0.82	-0.01				
Caregiver Somewhat Supported	-1.70	1.91	-0.13				
Caregiver Infrequent or No Support	-4.37*	2.15	-0.30				
Total Care Recipient Illness	-0.94	1.17	-0.11				
Spouse Relationship Type	-3.39	2.34	-0.20				
Other Relationship Type	0.18	1.95	0.01				
Rurality	0.98*	0.39	0.33				

Note. Caregiver Support was a categorical variable: Very Supported was the reference group. Relationship Type was a categorical variable: Adult child was the reference group.
*p<.05.

Table 6. Percentage of Knowledge of Long-term Services and Supports by Rurality in Caregiver County

Rurality[1]	Knowledge of Long-term Services and Supports (%)			Total (%)
	Low (0-9)	Medium (9.1-18)	High (18-26)	
2	58.3	23.7	22.5	27.8
3	8.3	21.1	7.5	13.3
4	0	13.2	12.5	11.1
6	25.0	26.3	37.5	31.1
7	8.3	10.5	12.5	11.1
8	0	2.6	0	1.1
9	0	2.6	7.5	4.4
Total (%)	100	100	100	100
N	12	38	40	90

Note. [1]USDA Rural-Urban Continuum Codes are from United States Department of Agriculture: Economic Research (2013), 2=Metro – Counties in metro areas of 250,000-1 million pop., 3=Metro – Counties in metro areas of fewer than 250,000 pop., 4=Non-metro – Urban pop. of 20,000 or more, adjacent to a metro, 6=Non-metro – Urban pop. of 2,500-19,999, adjacent to a metro, 7=Non-metro – Urban pop. of 2,500-19,999, not adjacent to a metro, 8=Non-metro – Completely rural or < 2,500 urban pop., adjacent to metro, 9=Non-metro – Completely rural or < 2,500 urban pop., not adjacent to metro.

Table 7. Percentage of Knowledge of Long-term Services and Supports by Perceived Levels of Support

Knowledge of Long-term Services and Supports	Perceived Levels of Support (%)			Total (%)
	No or Infrequent Support	Somewhat Supported	Very Supported	
Low (0-9)	28.6	12.0	5.0	13.6
Medium (9.1-18)	35.7	28.0	45.0	35.6
High (18.1-26)	35.7	60.0	50.0	50.8
Total (%)	100	100	100	100
N	14	25	20	59

Table 8. Percentage of Rurality in Caregiver County by Perceived Levels of Support

Rurality[1]	Perceived Levels of Support (%)			Total (%)
	No or Infrequent Support	Somewhat Supported	Very Supported	
2	21.4	28.0	50.0	33.9
3	28.6	12.0	10.0	15.3
4	7.1	12.0	0	6.8
6	28.6	28.0	25.0	27.1
7	14.3	16.0	10.0	13.6
9	0	4.0	5.0	3.4
Total (%)	100	100	100	100
N	14	25	20	59

Note. [1]USDA Rural-Urban Continuum Codes are from United States Department of Agriculture: Economic Research (2013), 2=Metro – Counties in metro areas of 250,000-1 million pop., 3=Metro – Counties in metro areas of fewer than 250,000 pop., 4=Non-metro – Urban pop. of 20,000 or more, adjacent to a metro, 6=Non-metro – Urban pop. of 2,500-19,999, adjacent to a metro, 7=Non-metro – Urban pop. of 2,500-19,999, not adjacent to a metro, 8=Non-metro – Completely rural or < 2,500 urban pop., adjacent to metro, 9=Non-metro – Completely rural or < 2,500 urban pop., not adjacent to metro.

Table 9. County-level Indicators Hypothesized to be Associated with Knowledge of Long-term Services and Supports

USDA Code[1]	Inadequate Social Support[2] (%)	# of Home Healthcare	# of Hospitals	On-time High School Graduation (%)	Associates Level Degree or Higher (%)	No High School Diploma (%)	Household Estimate Median Income ($)	Adult Overall Health Status[3] (%)	Medically Underserved Area
2	13.9	21	1	95.40	53.69	5.78	73,847	10.6	No
2	14.9	32	5	86.50	44.07	8.48	59,018	10.8	Yes
2	13.0	21	-	93.50	37.61	4.93	62,535	13.1	No
3	14.4	13	4	90.30	34.72	9.09	51,475	9.7	Yes
3	13.9	20	3	88.40	59.85	4.85	53,424	7.6	No
3	10.4	12	2	94.20	56.64	4.60	50,516	6.4	Yes
4	21.3	16	1	84.20	27.46	14.55	51,425	11.7	Yes
6	14.1	21	2	91.10	31.98	7.80	51,826	9.2	Yes
6	11.2	18	2	90.90	27.53	10.56	43,589	7.3	No
6	16.2	17	2	92.40	26.00	8.74	50,513	16.6	No
7	18.7	7	1	87.90	29.21	12.78	48,601	9.1	No
7	-	11	1	92.00	30.63	8.63	51,812	10.0	Yes
7	-	15	1	88.80	27.20	10.94	44,663	-	Yes
8	22.0	13	1	96.40	27.12	10.87	43,449	-	No
9	-	11	2	91.60	22.76	10.07	43,804	-	Yes

Note. [1]USDA Rural-Urban Continuum Codes are from United States Department of Agriculture: Economic Research (2013), 2=Metro – Counties in metro areas of 250,000-1 million pop., 3=Metro – Counties in metro areas of fewer than 250,000 pop., 4=Non-metro – Urban pop. of 20,000 or more, adjacent to a metro, 6=Non-metro – Urban pop. of 2,500-19,999, adjacent to a metro, 7=Non-metro – Urban pop. of 2,500-19,999, not adjacent to a metro, 8=Non-metro – Completely rural or < 2,500 urban pop., adjacent to metro, 9=Non-metro – Completely rural or < 2,500 urban pop., not adjacent to metro; [2]Percent of adults 18+ who reported inadequate social support; [3]Percent of adults 18+ who reported fair or poor health.

Table 10. Correlation of Participant Long-term Services and Supports Knowledge with County-level Variables

Variables	1	2	3	4	5	6	7	8	9	10
1. Knowledge of Long-term Services and Supports										
2. Rurality[1]	0.25* *n*=90									
3. Inadequate Social Support[2]	0.06 *n*=81	0.23* *n*=81								
4. # Home Healthcare	-0.10 *n*=90	-0.55** *n*=90	-0.16 *n*=81							
5. # Hospitals	0.02 *n*=87	-0.35** *n*=87	-0.26* *n*=78	0.66** *n*=87						
6. On-time High School Graduation	-0.16 *n*=90	-0.07 *n*=90	-0.64** *n*=81	-0.15 *n*=90	-0.27* *n*=87					
7. Associates Degree or Higher	-0.30** *n*=90	-0.79** *n*=90	-0.54** *n*=81	0.29** *n*=90	0.17 *n*=87	0.45** *n*=90				
8. No High School Diploma	0.21 *n*=90	0.46** *n*=90	0.80** *n*=81	-0.27* *n*=90	-0.21 *n*=87	-0.78** *n*=90	-0.76** *n*=90			
9. Median Income	-0.32** *n*=90	-0.76** *n*=90	-0.12 *n*=81	0.49** *n*=90	0.01 *n*=87	0.36** *n*=90	0.69** *n*=90	-0.52** *n*=90		
10. Adult Overall Health Status[3]	0.03 *n*=80	0.10 *n*=80	0.50** *n*=80	0.15 *n*=80	-0.02 *n*=77	-0.07 *n*=80	-0.42** *n*=80	0.18 *n*=80	0.14 *n*=80	
11. Medically Underserved Area	0.17 *n*=90	-0.01 *n*=90	0.09 *n*=81	0.12 *n*=90	0.35** *n*=87	-0.49** *n*=90	-0.03 *n*=90	0.16 *n*=90	-0.30** *n*=90	-0.32** *n*=80

Note. [1]USDA Rural-Urban Continuum Codes are from United States Department of Agriculture: Economic Research (2013), 2=Metro – Counties in metro areas of 250,000-1 million pop., 3=Metro – Counties in metro areas of fewer than 250,000 pop., 4=Non-metro – Urban pop. of 20,000 or more, adjacent to a metro, 6=Non-metro – Urban pop. of 2,500-19,999, adjacent to a metro, 7=Non-metro – Urban pop. of 2,500-19,999, not adjacent to a metro, 8=Non-metro – Completely rural or < 2,500 urban pop., adjacent to metro, 9=Non-metro – Completely rural or < 2,500 urban pop., not adjacent to metro; [2]Percent of adults 18+ who reported inadequate social support; [3]Percent of adults 18+ who reported fair or poor health.

*p<.05. **p<.01.

CHAPTER IV. REDUCING STRAIN AMONG CAREGIVERS OF PERSONS WITH DEMENTIA: THE HERO PROGRAM

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Literature Review

Fifty-nine percent of caregivers providing care to people with dementia rate their stress level as high or very high (Alzheimer's Association, 2017). People with dementia tend to require greater assistance from their caregivers compared to caregiving in the context of other diseases (Alzheimer's Association, 2017). Caregivers of people with dementia provide assistance with an average of two activities of daily living (e.g., eating, bathing) and five instrumental activities of daily living (e.g., managing finances, cleaning) and compared with other caregivers, they track the health of the care recipient more closely (Alzheimer's Association, 2017).

A variety of services are available to caregivers and care recipients, such as case management, counseling, support groups, respite care, and therapy (Pinquart & Sörensen, 2006). These approaches are often used to reduce burden and depressive symptoms experienced by caregivers of persons with dementia (Pinquart & Sörensen, 2006). There are also various in-person programs and interventions available specifically for caregivers of people with dementia to educate them on resources, help them accomplish their caregiving responsibilities, and manage their feelings of stress (Benjamin Rose Institute, 2016; Ducharme et al., 2011). However, due to the number of hours spent caregiving and the needs of the person with

dementia, it can be hard for the caregiver to leave and attend a program. To allow caregivers to be a part of a program and continue to care for their loved ones, certain programs are now being held over the phone (Smith & Toseland, 2006; Tremont, Duncan Davis, Bishop, & Fortinsky, 2008) or through other means of technology, such as the computer (Eisdorfer et al., 2003).

FITT-D (Family Intervention: Telephone Tracking – Dementia) is a telephone-based psychosocial intervention for caregivers of people with dementia in which the caregivers receive phone calls from a therapist to provide support and to focus on finding resources, the caregivers' needs, and coping (Tremont, Duncan Davis, Bishop, & Fortinsky, 2008). After the conclusion of FITT-D, caregivers reported lower perceived burden and fewer depressive symptoms (Tremont et al., 2008). Telephone Support Groups (TSG) are support groups for caregivers of older adults with physical and cognitive limitations in which education is provided to caregivers about the effects of chronic illnesses, coping strategies, problem-solving skills, and knowledge of services (Smith & Toseland, 2006). Caregivers in TSG reported a decrease in strain and depressive symptoms, as well as an increase in knowledge and use of services over time (Smith & Toseland, 2006). Caregivers enrolled in telephone-based interventions have reported a high level of satisfaction with the programs (Tremont et al., 2008).

The Health and Resilience Outreach (HERO) program is a telephone-based program and the overall goal is to enhance caregiver resilience, improve access to home and community-based services, and reduce health care costs. The HERO program is unique in nature because it recruits volunteers to call the caregivers to provide support and the volunteer calls as frequently as the caregiver needs. The volunteer also provides referrals to services that may be beneficial to the caregiver. The HERO program is also unique because it focuses on caregiver outcomes and also care recipient outcomes. If the caregivers are less strained and managing their caregiving

responsibilities more effectively, it is believed that this will translate to the care recipients and they will also benefit.

Theoretical Perspective

Feelings of support and interactions with others is important to being successful while caregiving. People are social in nature and therefore are dependent on interacting with others (Klein, White, & Martin, 2015). Due to this dependency, human behavior can be understood on an individual level and a population level; the environment in which this takes place consists of four systems that are related in which an individual interacts (Tudge, Mokrova, Hatfield, & Karnik, 2009). The microsystem is an environment in which a person spends time interacting with others and engaging in activities (Klein et al., 2015; Tudge et al., 2009). The mesosystem is the interrelations among multiple microsystems (Klein et al., 2015; Tudge et al., 2009). The exosystem is comprised of systems that have an indirect effect on the person and thereby their microsystems and mesosystems (Klein et al., 2015; Tudge et al., 2009). The macrosystem is the culture and society in which a person lives (Klein et al., 2015; Tudge et al., 2009). Caregivers find support in their microsystems, including interactions with family members, friends, and volunteers. The loved ones they are caring for also belongs in the microsystem. The interactions between these is the mesosystem and this is important to examine and see how it effects the caregiver.

Study Rationale

The Health and Resilience Outreach (HERO) program is an ongoing project that is funded through the Dementia Capable Grant and the Telligen Community Initiative (Iowa Department on Aging, 2014; Telligen Community Initiative, 2015). The program was designed and is administered by the Alzheimer's Association of Greater Iowa and represents a

collaboration with the Iowa Department on Aging and Iowa State University. The goal of the HERO program is to improve the resilience and overall well-being of caregivers, reduce cost of health care for individuals with dementia, and improve access to programs and services.

The HERO program is aimed at providing informal caregivers of people with dementia with support and resources through phone interventions with a volunteer (Iowa Department on Aging, 2014; Telligen Community Initiative, 2015). The volunteers are available to provide emotional support to the caregivers as well as suggestions for resources based on caregiver and care recipient needs. As a funded project, HERO also has an allotted amount of money available to caregivers in order to access direct services each month. These services are available to provide caregivers with additional help and respite in their caregiving tasks.

To address a gap in the literature, this study investigated influences at the individual, dyadic, and program level on program efficacy. This study analyzed the dosing of the HERO program by examining the frequency of calls made by the volunteers. Examining HERO participation provided an understanding of dosing levels related to decreased strain among caregivers. Health surveillance of the care recipient was examined to understand the relationship of care recipient health and caregiver strain. Caregiver relationships (e.g., adult child, spouse) was also studied to understand caregiver experiences as related to strain and HERO program participation.

Research Questions

My first research aim was to investigate the change over time in caregiver reports of strain. I hypothesized that MCSI levels would be stable across time or decrease due the support provided through the HERO program. My second research aim was to identify predictors of

caregiver strain. I hypothesized that better care recipient health status, being an adult child, and a higher amount of calls (i.e., more HERO participation) would result in lower MCSI scores.

Method

Design and procedure

The HERO program was designed to be a volunteer-based program. Volunteers were continuously recruited through a variety of ways including health fairs, board of nursing newsletters, volunteermatch.com, the Alzheimer's Association website, support groups, educational sessions, and homecare companies. Interested persons submitted an application, completed a background check, and went through an interview. Selected individuals were trained in the HERO process and documentation and they also went through a dementia training. There were bimonthly training opportunities and volunteers were also invited to the annual Alzheimer's Association conference. Once trained, volunteers were assigned one to five caregivers. The expectation was that volunteers call each of their designated caregivers at least once per month. The volunteer was responsible for collecting selected data during their phone calls with the caregiver including health of the person with dementia (i.e., health surveillance) and hospitalizations for both the care recipient and caregiver. During the initial call upon enrollment and approximately every two months after, the volunteers collected information from the Modified Caregiver Strain Index (MCSI; Thornton & Travis, 2003).

In addition to providing support, another aspect of the HERO program was the direct service dollars, which were available to help provide services to caregivers. When caregivers inquired about the direct services dollars, volunteers ascertained why caregivers were not accessing home and community-based services and if finances were a constraining factor. Volunteers then began to discuss the direct service dollars. This process was on a first-come,

first-served basis. In the final year of the HERO project, there was a limit of $150.00 a month, previously the limit had been $250.00 a month. There was a wait list that was utilized if the dollars were unavailable due to existing participants using the allotted amount of direct service dollars. In this instance, participants who had been placed on the wait list were taken off and offered the direct services dollars as participants discharged from the HERO project who had been using the direct service dollars.

Participants

The original strategy was to recruit caregivers via a managed health care organization. However, over time HERO began to recruit participants from a variety of organizations, such as physicians' offices, home care companies, but followed the same enrollment process. Caregivers were provided with a soft referral, which occurred when an organization identified a caregiver they believed was in need of the HERO program and provided the Alzheimer's Association with contact information to follow-up with the caregiver. The organizations could call or email the Alzheimer's Association as well to providing a referral. Those who chose to continue with the call had the opportunity to initiate a volunteer support plan and enroll in the HERO program.

At the point of data analysis, 112 caregivers and 113 people with dementia (PWD) had participated in the HERO program. Together these caregivers and PWD created 111 caregiving dyads and one caregiving triad. Thirty-one were adult child/parent dyads, 72 were spouse/spouse dyads, and nine were other relationship dyads (e.g., friend/friend, grandmother/granddaughter). Ninety-one caregivers were female (21 male) and 70 PWD were male (43 female). The average age of the caregiver was 66 years (*SD* = 12.7, *Range* 25-84). The average age of the PWD was 78 years (*SD* = 9.1, *Range* 49-98). See Table 1 for HERO participant demographics.

Measures

Caregiving Demographics. When the caregivers enrolled in HERO, they were asked a series of demographic questions including age and relationship to the person with dementia (e.g., parent and child, spouse). Within the main analysis, caregiver relationship was examined at two levels, spouse and adult child, the other category was excluded.

Caregiver Burden. The Modified Caregiver Strain Index (MCSI) was used to measure the degree of strain a caregiver is feeling. The MCSI consists of 13 items used to measure strain in relation to providing long-term care (Thornton & Travis, 2003). Examples include emotional adjustments due to caregiving, difficulty sleeping, and the financial strain of caregiving. Items are scored on a three-point response scale (i.e., No = 0; Yes, Sometimes = 1; Yes, On a Regular Basis = 2) based on the frequency of occurrence. The final score represents a total summed score with a range of zero to 26, with zero being the lowest reported caregiver strain and 26 being the highest caregiver strain (α =.90; Thornton & Travis, 2003). The value of Cronbach's alpha within this study was .85 for Wave 1 (n = 42), .85 for wave 2 (n = 53), and .82 for Wave 3 (n = 42). The MCSI was intended to be administered to participants upon enrollment and then every two months by the volunteers. However, not all participants received the MCSI every two months and thereby have missed waves. See Table 2 for MCSI wave totals, missing wave totals, and the mean scores. Also, see Figure 1 for a graph of the individual caregiver MCSI totals across the waves. At the time of this study, there had been a maximum amount of 11 waves of the MCSI. The time between waves is considered an interval (e.g., MCSI Wave 1 to MCSI Wave 2 is interval 1-2).

Health Surveillance. The HERO program designers developed a brief health surveillance tool in consultation with a managed care company to assess important health indicators for the

care recipient. The health status questionnaire was administered every time the volunteer called the caregiver. The measure consists of eight yes/no questions associated with deteriorating health and increased likelihood of difficult in-home care and potential hospitalization (i.e., fall, wandering, bathroom safety concerns, other safety concerns, difficulty eating, problems with other chronic illnesses, hospitalization, medication change). An opportunity to elaborate on the health-related difficulties was available at some occasions. After examining this "other" category, the item regarding medication change was excluded. Based on the open-ended responses, it was apparent this item did not clearly show a negative health behavior exhibited by the care recipient, unlike the other seven questions. Based on these seven items, a total score was created, ranging from zero to seven, with a higher score indicating more negative health behaviors reported in the care recipient. Health surveillance was included as a covariate. Taking into consideration that there were multiple indicators of this variable over time, the interval preceding the MCSI for that particular wave was summarized. The health surveillance was indicated by an average of the health surveillance scores during the relevant interval (see Table 3).

HERO Intervention Dosing. The total number of phone contacts was used for analysis of HERO program dosing. Program dosing was included as a covariate. As there were multiple indicators of dosing across time, the interval prior to the MCSI for that particular wave was summarized. Program dosing was assessed by examining the total number of calls during the relevant interval (see Table 4). Also, see Figure 2 for a graph of the call frequencies within each interval.

Analytic plan

To examine change in MCSI total scores and predictors of strain, generalized linear models were estimated. Throughout the course of the HERO program, implementation was dependent on both volunteer and caregiver responsiveness. As a consequence, the resulting MCSI data consisted of missing data points. We followed the statistical approach of Kim et al. (2004). This approach took into account the repeated measures of the MCSI while allowing for participants from all available waves to be included. The dependent variable was the total score of the MCSI at each occasion. The independent variables included caregiver age, relationship type, MCSI time, MCSI Wave 1 (as control variable) care recipient health surveillance, and HERO program participation. The model was employed with each independent variable individually. Then, after initial findings were analyzed, groups of independent variables were run together in larger models with the dependent variable. Overall, the proposed analyses described the change over time in the MCSI as well as examined individual, dyadic, and program predictors.

Results

To characterize change over time in caregivers' reports of strain, MCSI total scores were reviewed for each individual participant across all waves (see Figure 1). First, the range of the MCSI total score was divided into four quartiles and each participants' total score was placed into the corresponding quartile. This was repeated for all waves available per individual. After analysis of caregivers' trajectories, categories were created based on if a caregiver's reported strain remained within a particular quartile or varied across time. The figures in Appendix C depict the quartile categories represented by multiple graphs. It was observed that many caregivers maintained the same level of stress over time; once they began in a quartile they

tended to remain within it over time. These caregivers who maintained their stress levels over time were seen either in a low, moderate, or high category. There were also some caregivers who had totals scores that increased over time and moved up through the quartiles. As well as a few caregivers who reported declining scores over time. Lastly, there were individuals who were not able to be placed into a category due to a high degree of missing strain reports across waves.

Next, to investigate predictors of strain in caregivers of people with dementia, we first estimated a generalized linear model. First, the independent variables were analyzed individually with the dependent variable. Relationship type (p = .001), gender (p =.027), MCSI Wave 1 (p < .001), age (p < .001), and program dosing (p = .033) were individually significant predictors of strain.

After initial analyses, a full generalized linear model included the independent variables relationship type, Wave 1 of the MCSI (to serve as a control variable), MCSI time, age, health surveillance, and dosing. Together, the overall model included 66 cases and was significant (likelihood ratio $\chi^2 = 82.14$, $df = 25$, $p < .001$). Relationship type (p < .001), MCSI Wave 1 (p < .001), age (p < .001), and health surveillance (p = .028) were significant predictors of MCSI (see Table 5). Gender was not included in the full model due to a small cell size of males. Other relationship type was also excluded from the full model due to a small cell size. Interaction effects (e.g., age by relationship type) were attempted in this model but were not able to be analyzed due to small cell sizes and missing data.

Due to the small inclusion size of the full model (n = 66), another model was estimated that did not include the control variable of MCSI Wave 1 which allowed for a larger sample size (n = 152). Gender and other relationship type were also included in this model as they had sufficient cell sizes. The resulting model was significant (likelihood ratio $\chi^2 = 47.80$, $df = 15$, p

< .001) and included relationship type ($p = .03$) and age ($p < .001$) as significant predictors of MCSI (see Table 6).

Discussion

The aim of this study was to examine caregiver strain over time as well as to identify characteristics, both at the personal and program levels, related to increased levels of strain in caregivers of people with dementia. After examination of the levels of strain over time, it was found that categories can be created to group together caregivers who maintain, increase, or decline their levels of strain over time. Maintaining the level of strain, rather than increasing in strain, can be viewed positively for caregivers due to progressive nature of dementia and the unknown events occurring within the caregivers' lives that could be potential stressors. The main populations of concern to target with interventions and other services and supports would be caregivers with continually high levels of strain and those increasing in their strain.

The findings of this study revealed that the personal level characteristics were important in understanding increased levels of strain in caregivers. Age of the caregiver was a significant predictor of strain. The results indicated that younger caregivers reported higher levels of strain. The dyadic level characteristics were also important in understanding strain. First, the relationship type was a significant predictor of strain, indicating that spouses reported higher levels of strain. Also, it was indicated that an increased number of changes in health behaviors in the care recipient predicted higher levels of strain in the caregiver. These findings demonstrate that the relationship and interactions between the caregiver and the care recipient is important to fully understand. However, it is important to note that age and relationship type may be confounding variables as most spouses are older in age and most adult child caregivers are younger in age, however, the interaction effect between these variables was not able to be tested

in this study. Lastly, the initial Wave 1 MSCI score was predictive of future MCSI scores. Thereby, initial levels of strain are indicative of future levels of strain in caregivers.

Identifying these personal and dyadic level factors related to caregiver strain applies the bioecological theory and its four interrelated systems, including the microsystem, mesosystem, exosystem, and macrosystem. Personal level can affect strain as well as relationships with others, as the findings of this study indicated in the dyadic relationship with the care recipient. Community level influence can also affect caregiver level of strain through access to programs and services in the area as well as effective program communication and interaction with caregivers. Programs should continue to become increasingly available to caregivers, specifically caregivers who are hard to reach due to their location and caregiving responsibilities. Having further programs offered over the phone or online is one potential solution to making programs more accessible to caregivers.

After analysis of the HERO program, there were future directions identified for the HERO program as it continues to be implemented and disseminated to other locations. One future direction for the HERO project would be to create a measure of fidelity to ensure that the volunteers are providing support, referring resources, and collecting data. There are many differences within the volunteers, so this may be a way to ensure all volunteers are completing their tasks correctly and fully. The volunteer differences would be an interesting item to explore as these differences may affect the caregiver and how they feel about the HERO program. Also, additional measures would be beneficial in understanding the caregiver and their caregiving situation more fully. Additional measures could include a measure of caregiver health, feelings of support, and a resiliency measure. Lastly, another future direction involves the frequency and consistency of data collection. Data collection could occur in a less frequent manner as to not

overwhelm the volunteer or the caregiver, such as collecting the data every two months and within the same phone call for all caregivers. These suggestions for the HERO program may help it to be successful and continue to help caregivers in the best ways possible in the future.

Limitations and future directions

There were limitations to this study. First, all measures used were self-reported by the caregiver, including the MCSI and the health surveillance of the care recipient. Second, as mentioned above, we were not able to test all interaction effects in this study, including interactions between relationship type and age. Future researchers should examine factors that were unknown in this study that could have influenced the level of burden being experienced by the caregiver, such as the level of support that was provided by the volunteer and the care recipient's stage of dementia.

There are many potential avenues for future research to take to continue to understand caregiver strain. First, future researchers should collect more information from the caregivers to be able to fully understand their caregiving situation. For example, researchers should examine the caregivers' health as this may be an additional indication of caregiver strain. Another potential avenue for future research is to examine the MCSI at the item-level to analyze the potential differences in the feelings of strain. For example, there may be a difference in emotional strain versus physical strain and this may change over time throughout their caregiving journey. Also, future research should try to collect an observer report, such as from a secondary caregiver or an interviewer, along with the caregiver's self-report. It would be beneficial to have a multi-method approach in the future. Lastly, even though program dosing was not found to be a significant predictor of lower levels of strain in this study, future

researchers should expand upon this area of research and gain a better understanding of the effects individualized support has on caregivers.

Conclusion

The extant literature demonstrates that caregivers experience strain during their caregiving journey. After identifying characteristics of caregivers who are more likely to experience higher levels of strain, it is important that programs and interventions target these caregivers and aim to help them manage their feelings of strain. These caregivers may be more difficult to reach due to their caregiving situations (e.g., finances, location, transportation), which present varied needs. Thus, it is important to offer a variety of different programs that may be delivered in various ways, such as in-person, via phone, or online. Overall, a variation of programs will allow a wider variety of caregivers to become involved with beneficial programs.

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Table 1. HERO Participant Demographics (*N* = 112 Caregivers)

	M (*SD*)	*Range*
Caregiver Age	65.9 (*12.7*)	25-84
Person with Dementia Age	78.3 *(9.1)*	49-98
	Frequency	Percentage
Caregiver Sex		
Male	21	18.8
Female	91	81.3
Person with Dementia Sex		
Male	70	61.9
Female	43	38.1
Caregiver Race		
White	107	95.5
African American/Black	4	3.6
Person with Dementia Race		
White	108	95.6
African American/Black	4	3.5
Native Hawaiian	1	0.9
Caregiver Relationship		
Child	31	27.7
Spouse	72	64.3
Other	9	8.0

Table 2. Modified Caregiver Strain Index Sample Size and Total Score Average by Occasion (*N* = 112)

	Participants Providing Scores	Missing[a]	*M*
Wave 1	42	38	13.26
Wave 2	53	16	13.96
Wave 3	42	8	13.57
Wave 4	27	15	14.85
Wave 5	22	8	15.50
Wave 6	20	5	16.90
Wave 7	16	2	15.19
Wave 8	7	3	17.14
Wave 9	6	0	15.00
Wave 10	2	0	18.00
Wave 11	1	0	21.00

Note: [a] Participants were enrolled in the program during each wave; however, a Modified Caregiver Strain Index was not available.

Table 3. Average Number of Health Behavior Changes Observed by Caregivers during each Interval

Interval	1-2	2-3	3-4	4-5	5-6	6-7	7-8	8-9	9-10	10-11	11-12	12-13
Valid *N*	57	60	51	38	25	21	14	10	7	2	1	1
M	.63	.47	.42	.49	.38	.43	.18	.37	.29	.10	.50	2.0
Range	0-2	0-3	0-3	0-6	0-3	0-2	0-0.67	0-2.4	0-2	0-0.2	-	-
Number of Changes	*N* (valid %)											
0	19 (33.3)	28 (46.7)	27 (52.9)	20 (52.6)	15 (60.0)	11 (52.4)	9 (64.3)	8 (80.0)	6 (85.7)	1 (50.0)	0	0
1 or less	31 (54.5)	26 (43.3)	19 (37.4)	14 (36.7)	9 (36.0)	7 (33.4)	5 (35.6)	0	0	1 (50.0)	1 (100)	0
1 - 2	7 (12.3)	5 (8.4)	4 (7.9)	3 (7.9)	0	3 (14.4)	0	1 (10.0)	1 (14.3)	0	0	1 (100)
2 - 3	0	1 (1.7)	1 (2.0)	0	1 (4.0)	0	0	1 (10.0)	0	0	0	0
3 +	0	0	0	1 (2.6)	0	0	0	0	0	0	0	0

Table 4. Frequency of Calls during each Interval

Interval	*M*	*SD*	*Range*
1-2	1.36	1.6	0-8
2-3	1.99	1.8	0-8
3-4	2.05	2.0	0-10
4-5	1.90	1.8	0-7
5-6	1.97	1.8	0-6
6-7	2.11	1.9	0-6
7-8	2.24	1.9	0-7
8-9	2.18	1.8	0-6
9-10	1.63	1.3	0-4
10-11	5	0	5
11-12	4	-	4
12-13	1	-	1

Table 5. Generalized Linear Model for Modified Caregiver Strain Index (n = 66)

Variables	Wald χ^2	*df*	*p*
Relationship Type	13.86	1	<.001
Modified Caregiver Strain Index Wave 1 (Control)	96.05	12	<.001
Modified Caregiver Strain Index Time[1]	8.93	9	.44
Caregiver Age	15.03	1	<.001
Care Recipient Health Surveillance[2]	4.85	1	.03
HERO Program Dosing[3]	1.39	1	.24

Note. This model includes the control variable of Modified Caregiver Strain Index Wave 1. Adult child was the reference group for Relationship Type. Total score of 26 was the reference group for Modified Caregiver Strain Index Wave 1 (Control). Wave 9 was the reference group for Modified Caregiver Strain Index Time. [1]Modified Caregiver Strain Index waves over time; [2]Mean number of health behaviors in the care recipient in each interval over time; [3]Total number of phone contacts in each interval over time.

Table 6. Generalized Linear Model for Modified Caregiver Strain Index (n = 152)

Variables	Wald χ^2	*df*	*p*
Relationship Type	7.17	2	.03
Caregiver Gender	2.13	1	.14
Modified Caregiver Strain Index Time[1]	14.49	9	.11
Caregiver Age	15.90	1	<.001
Care Recipient Health Surveillance[2]	3.01	1	.08
HERO Program Dosing[3]	.05	1	.83

Note. This model does not include the control variable of Modified Caregiver Strain Index Wave 1. Other relationship type was the reference group for Relationship Type. Male was the reference group for Caregiver Gender. Wave 9 was the reference group for Modified Caregiver Strain Index Time. [1]Modified Caregiver Strain Index waves over time; [2]Mean number of health behaviors in the care recipient in each interval over time; [3]Total number of phone contacts in each interval over time.

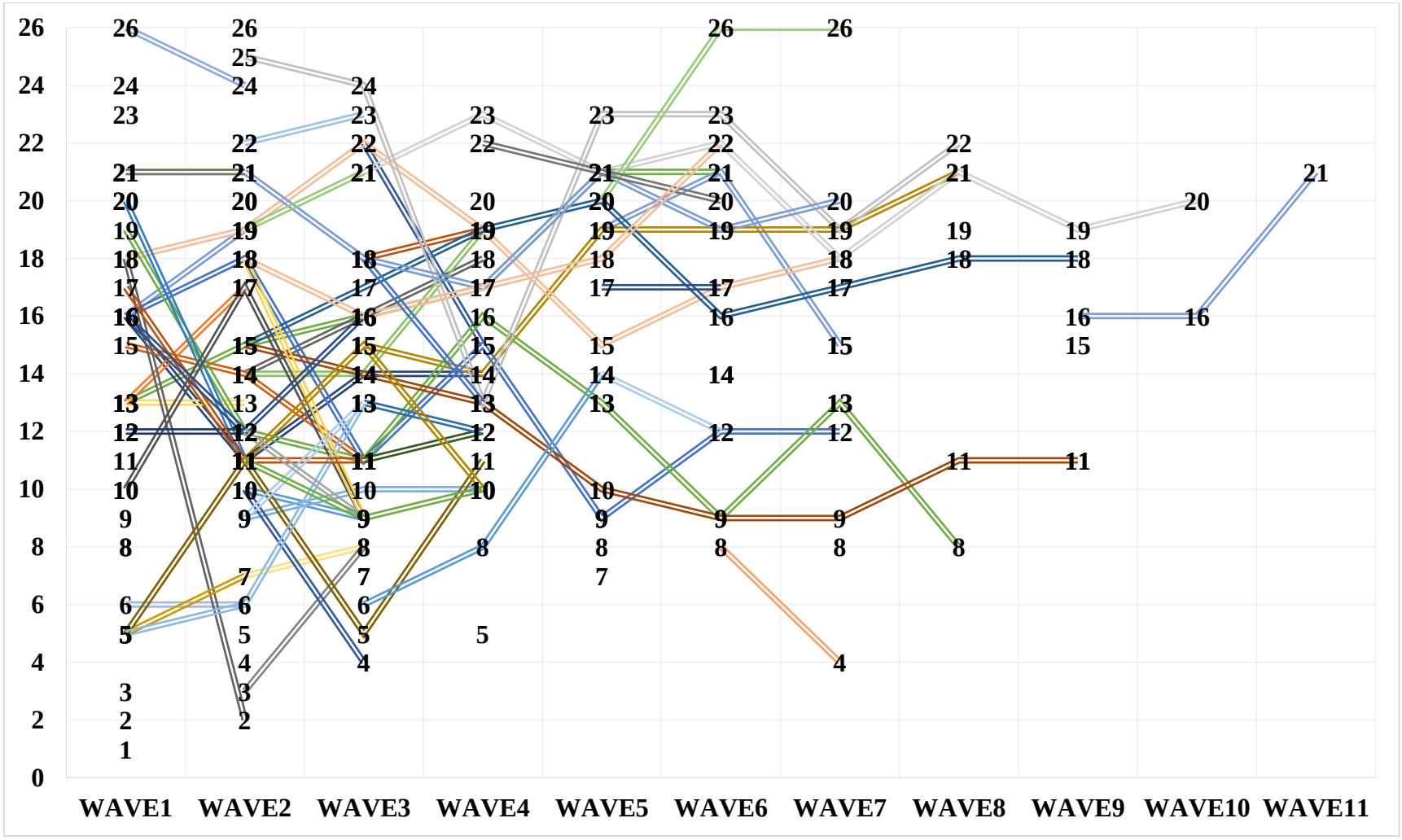


Figure 1. Modified Caregiver Strain Index Totals by Occasion per Individual Case

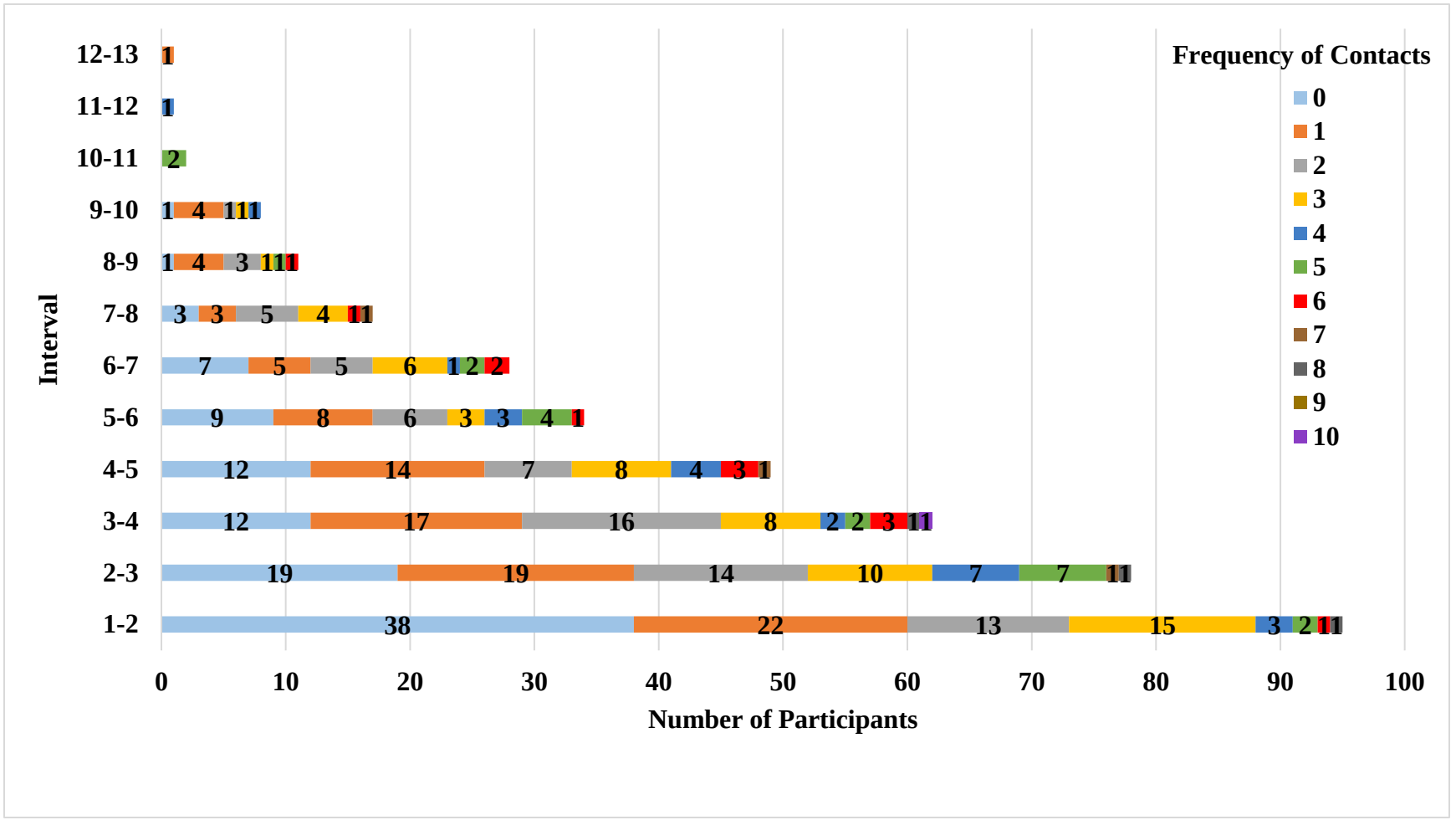


Figure 2. Frequency of Participants' Contacts within HERO Participation Intervals

CHAPTER V. DISCUSSION

Caregivers are a large and often underserved population who tend to experience strain due to caregiving responsibilities. There is a need to understand how to provide better support to caregivers thereby supporting the care recipients. This thesis offered an opportunity to examine two programs that were aiding in the effort to support caregivers and provide them with resources and knowledge to help them with their caregiving responsibilities. Overall, this thesis was conducted to acquire a better understanding of caregivers who are in need of more accessible resources and support.

Though both studies examined two different outcomes, caregiver knowledge of long-term services and supports (LTSS) and caregiver strain, there were similarities noted in the findings of both manuscripts. In study 1, the findings indicated that caregivers living in more rural areas were more likely to have higher knowledge of LTSS. Additionally, caregivers with feelings of infrequent or no support reported lower levels of knowledge of LTSS. These findings suggest that personal characteristics are partially to account for level of knowledge but also county-level characteristics. Similarly, study 2 results revealed that personal characteristics (i.e., caregiver age) accounted for caregiver strain along with characteristics at a dyadic level (i.e., relationship type and health status of the care recipient) accounted for caregiver strain. Both of these findings provide an understanding about the characteristics that affect caregiver knowledge of LTSS and strain at both a personal level as well as other levels, such as county and community. Furthermore, by increasing the understanding about the factors impacting caregiver knowledge and strain, future efforts directed to improving the lives of caregivers will be better informed and more effective.

Despite the broad implications of the findings in both studies, there are differences to be discussed between Caregiver Beginnings Workshop and HERO. Most notably there were differences in how the programs were delivered and the intended population of caregivers each program reached. First, the method of referral for program admission differed. Opportunity to participate in HERO occurred via both referral from a health care organization as well as response to advertisement and outreach efforts. The Caregiver Beginnings program was based on self-referral into the program. The programs also differed in target audience. HERO was offered specifically to caregivers of people with dementia whereas Caregiver Beginnings was open to all caregivers. Next, HERO volunteers interact with caregivers via the phone whereas Caregiver Beginnings was an in-person session. Lastly, the programs differed in duration. HERO lasted for extended period of time, dependent on caregiver need and desire for program enrollment, whereas Caregiver Beginnings was a one-time session. Differences in recruitment, target audience, duration, and mode of delivery likely created a difference in the population of caregivers enrolled in each program. A majority of spousal caregivers were enrolled in HERO, whereas adult-child caregivers comprised the bulk of caregivers participating in Caregiver Beginnings.

This difference in program implementation and program participation should be a consideration for future programming and research. Certain types of programs may be most appealing to a specific type of caregiver due to participant recruitment, time commitments, and program medium. Therefore, programs should be offered to a variety of target audiences and differing delivery methods should be utilized as to be engaging to all types of caregivers.

Limitations

Both papers had similar limitations that are important to discuss and make note of for future research. Both studies used measures that were self-reported by the caregiver. Often, self-reported data are not as reliable as other methods of data collection that may give more insight to the extent of caregiver strain, like observation or records. In addition, both studies had relatively small sample sizes, which likely led to underpowered analyses. Since caregivers have many responsibilities and are potentially under stress at the time of recruitment, inclusion of caregivers in research can be difficult resulting in a reluctance to participate in research and potentially incomplete data collection. Lastly, in addition to a small sample size, both studies also had missing data. This was accounted for by imputation and analyses that attempted to address the limited sample size.

Future Directions

Caregiving situations are likely to be unique to each individual, as to when they categorize themselves as caregivers, different trajectories of health in the care recipient and perhaps the caregiver, and different contexts in which the caregiving is taking place (e.g., in-home, assisted living, long-distance). Future researchers should expand on the information collected from the caregivers in order to fully understand each unique caregiving circumstance and how caregiving situations affect knowledge as well as burden. Information should be collected about secondary caregivers that may be helping with the caregiving responsibilities, such as medical or financial power of attorney. Family and interpersonal dynamics may vary and in some contexts more caregivers could potentially mean increased strain. The specific caregiving responsibilities performed by the caregiver, such as helping with activities of daily living or finances, should be collected as well. This would provide insight into the caregiving

responsibilities that result in higher levels of strain for caregivers. Information should be collected on the number of care recipients, if the caregiver is providing care for more than one older adult, as well as if they are providing care for a child. Lastly, the length of caregiving should be collected as this may affect the level of strain that is experienced in caregivers. Overall, more care should be taken when considering which factors impact the wellbeing of caregivers. By acquiring more accurate and representative information about the lives of caregivers, efforts to prepare and positively impact caregivers and their loved ones will be more effective.

CHAPTER VI. CONCLUSION

Caregivers and the situations they are caregiving in need to be assessed on multiple levels to provide a comprehensive picture of the caregiving experience and how to best provide help across various types of caregivers. There are many different contexts in which examining caregiving situations is possible. One context is an area or county-level, such as through the level of rurality the caregiver is residing in or the resources that are available in the area. Another context is a dyadic level, for instance examining the relationship between the caregiver and the care recipient. Another context that can be examined is a personal level, such as looking at the caregiver's perceived levels of support or age. Achieving further research in these areas will ultimately help to shape programs that are context-specific to the various needs of caregivers. Therefore, understanding different levels and individual situations that caregivers are in is the key to providing assistance and information and potentially resulting in reduced levels of strain, increased levels of support, and increased levels of knowledge of available resources in the caregivers. Providing support and additional resources to caregivers through programs and policy is an important implication of this research that will benefit both the caregivers and the care recipients.

APPENDIX A

HUMAN SUBJECTS APPROVAL STUDY 1: CAREGIVER BEGINNINGS WORKSHOP

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-4566
FAX 515 294-4267

Date: 3/4/2016

To: Lauren Stratton
564 W Goodwin St.
Ankeny, IA 50023

CC: Dr. Jennifer Margrett
4380 Palmer

From: Office for Responsible Research

Project Title: Informal caregivers' knowledge on long-term services and supports

The Co-Chair of the ISU Institutional Review Board (IRB) has reviewed the project noted above and determined that the project:

☐ Does not meet the definition of research according to federal regulations.

☒ Is research that does not involve human subjects according to federal regulations.

Accordingly, this project does not need IRB approval and you may proceed at any time. We do, however, urge you to protect the rights of your participants in the same ways you would if IRB approval were required. For example, best practices include informing participants that involvement in the project is voluntary and maintaining confidentiality as appropriate.

If you modify the project, we recommend communicating with the IRB staff to ensure that the modifications do not change this determination such that IRB approval is required.

APPENDIX B

HUMAN SUBJECTS APPROVAL STUDY 2: HERO PROGRAM

---------- Forwarded message ----------
From: **IRB Committee [ORR]** <irb@iastate.edu>
Date: Fri, Mar 4, 2016 at 10:42 AM
Subject: RE: IRB review questions for #16-080 (Stratton)
To: "Stratton, Lauren R [HD FS]" <stratton@iastate.edu>, "IRB Committee [ORR]" <irb@iastate.edu>
Cc: "Margrett, Jennifer [HD FS]" <margrett@iastate.edu>

Hi Lauren,
Thanks for your response. Based on that information, I have determined that you do not need IRB oversight for #16-080, as you will not have any interaction or intervention with participants (i.e. data is all existing). Further you have indicated that it will be received completely de-identified – meaning there is no key linking the study ID codes to identity, nor is there any potentially identifying information in the data set (in other words data that you could put together to determine identity).

I looked at #15-515, as with #16-080 we had made a determination that the research was not subject to IRB oversight,. In our understanding of #15-515, the data, while sensitive, was received by ISU completely de-identified, with no way to directly or indirectly identify individuals. Additionally, ISU personnel had no interaction or intervention with the participants, rather the role was only to look at de-identified data collected by someone else. Provided that all of that is true, you would not need IRB oversight to use the existing, de-identified data from #15-515.

I will send out an official determination letter for #16-080, hopefully yet today.

Best,
Jen

Jennifer Ensley Gorshe
IRB Administrator | IRB Post Approval Monitor
Office for Responsible Research | Iowa State University
1138 Pearson Hall | Ames IA 50011
515-294-7792 | 515-294-4267 fax

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-4566
FAX 515 294-4267

Date: 9/29/2015

To: Dr. Jennifer Margrett
4380 Palmer

CC: Dr. Mack Shelley
1413 Snedecor Hall

From: Office for Responsible Research

Project Title: Creating a dementai-capable HCBS system in Iowa: Greater Iowa Alzheimer's Association HERO Project

The Co-Chair of the ISU Institutional Review Board (IRB) has reviewed the project noted above and determined that the project:

☐ Does not meet the definition of research according to federal regulations.

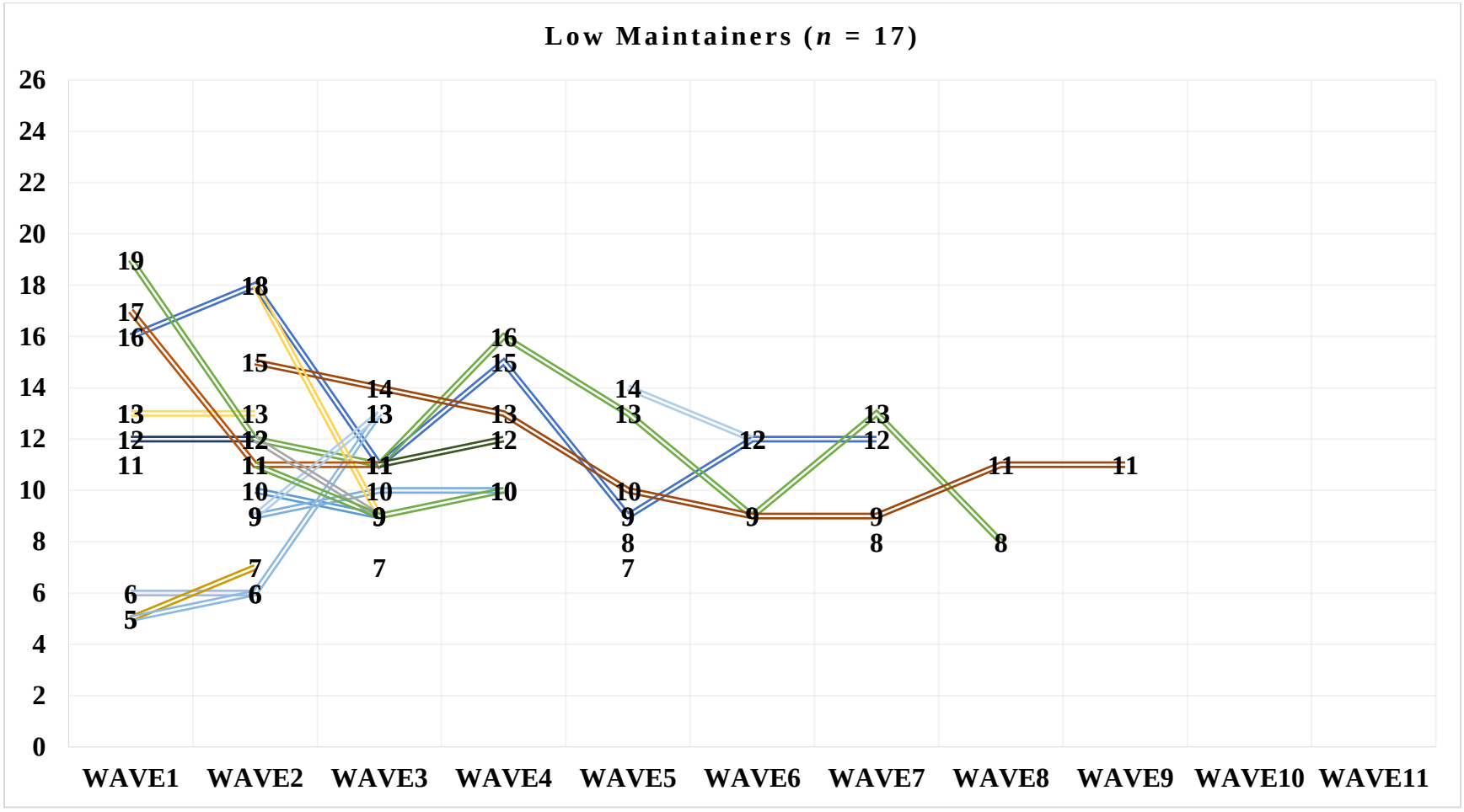
☒ Is research that does not involve human subjects according to federal regulations.

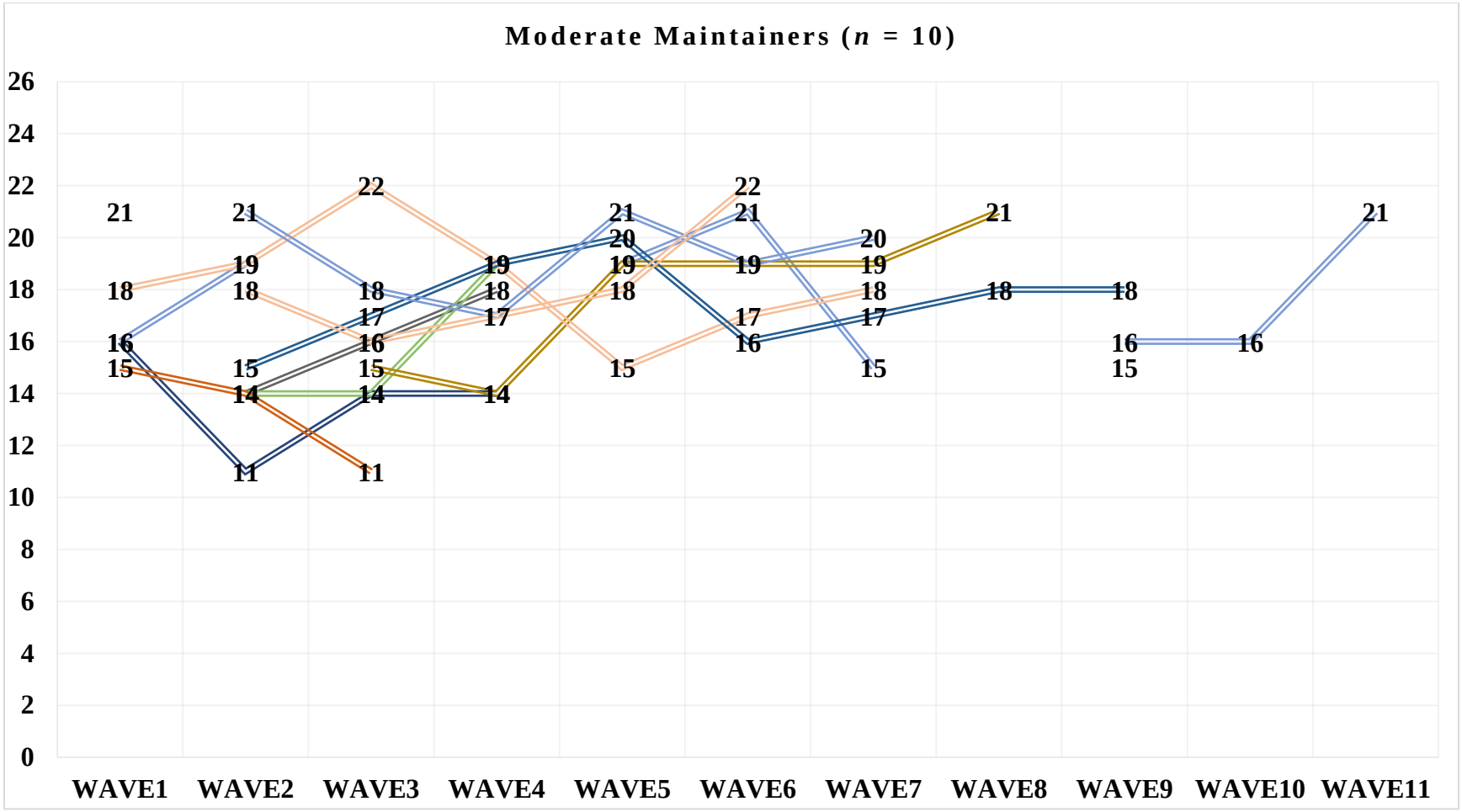
Accordingly, this project does not need IRB approval and you may proceed at any time. We do, however, urge you to protect the rights of your participants in the same ways you would if IRB approval were required. For example, best practices include informing participants that involvement in the project is voluntary and maintaining confidentiality as appropriate.

If you modify the project, we recommend communicating with the IRB staff to ensure that the modifications do not change this determination such that IRB approval is required.

APPENDIX C

HERO MODIFIED CAREGIVER INDEX QUARTILES




Moderate Maintainers (n = 10)
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20
18
16
14
12
10
8
6
4
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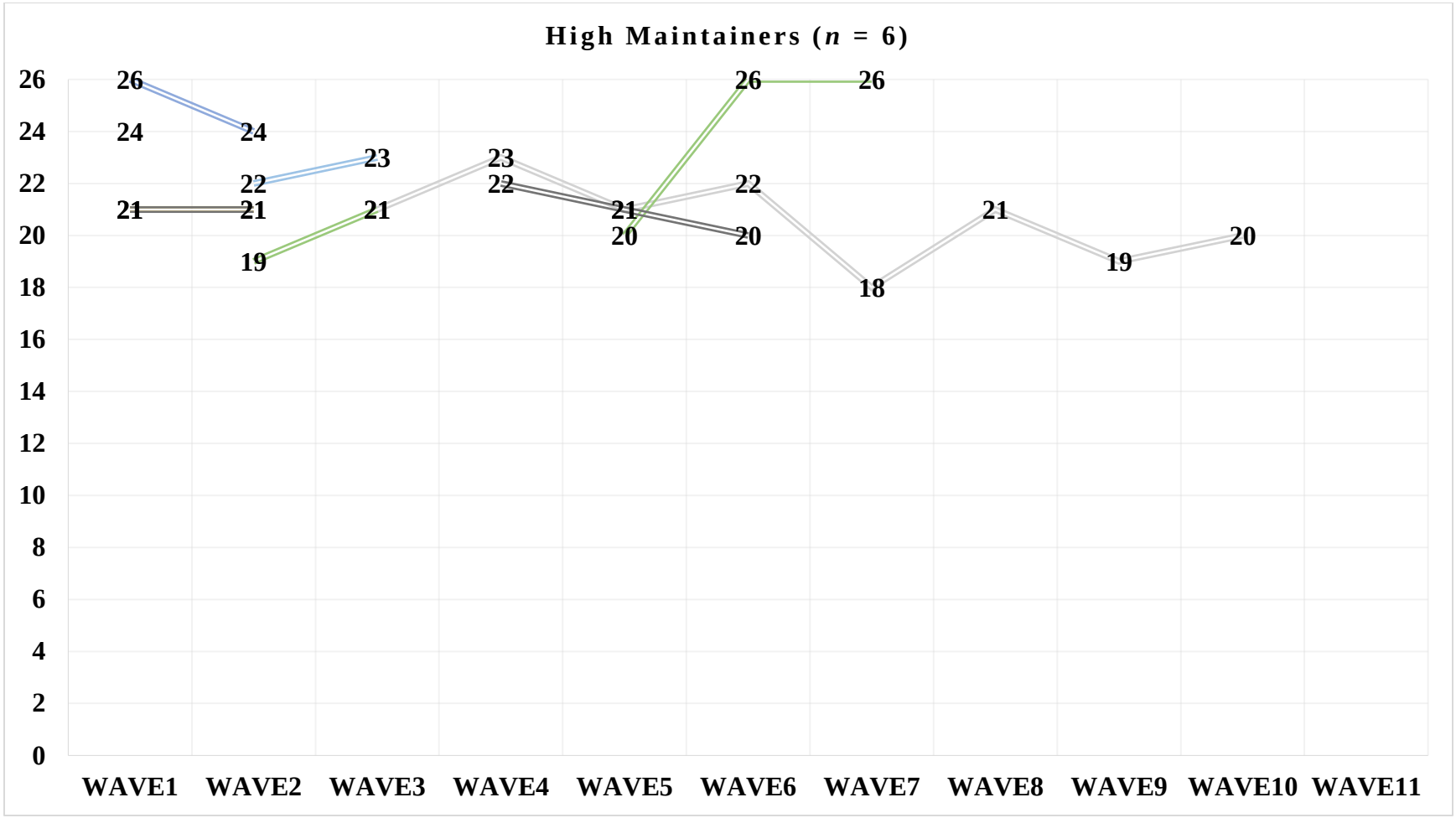
WAVE9
WAVE10
WAVE11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16
14
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10
8
6
4
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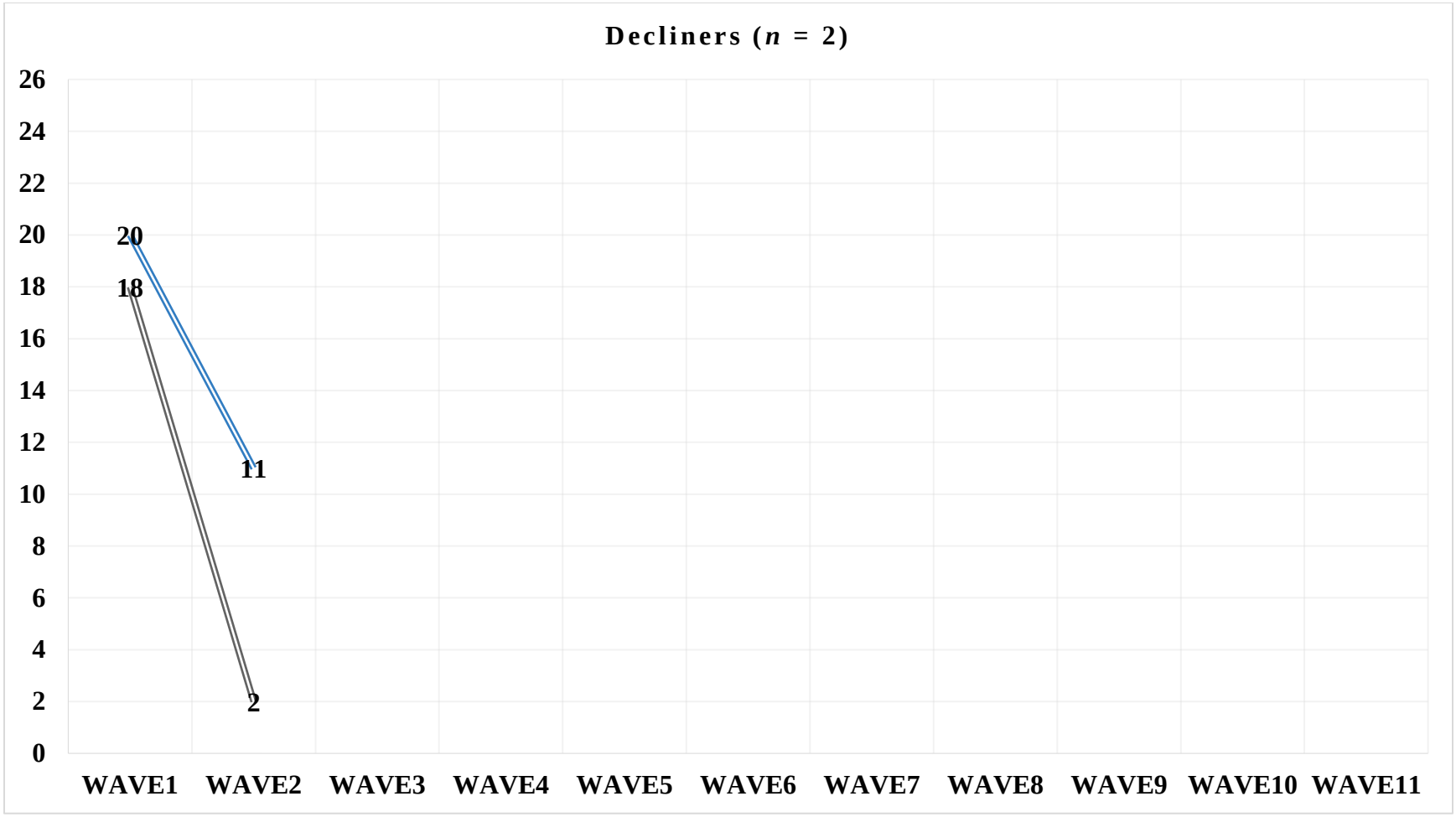
WAVE9
WAVE10
WAVE11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18
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14
12
10
8
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4
2
0
20
18
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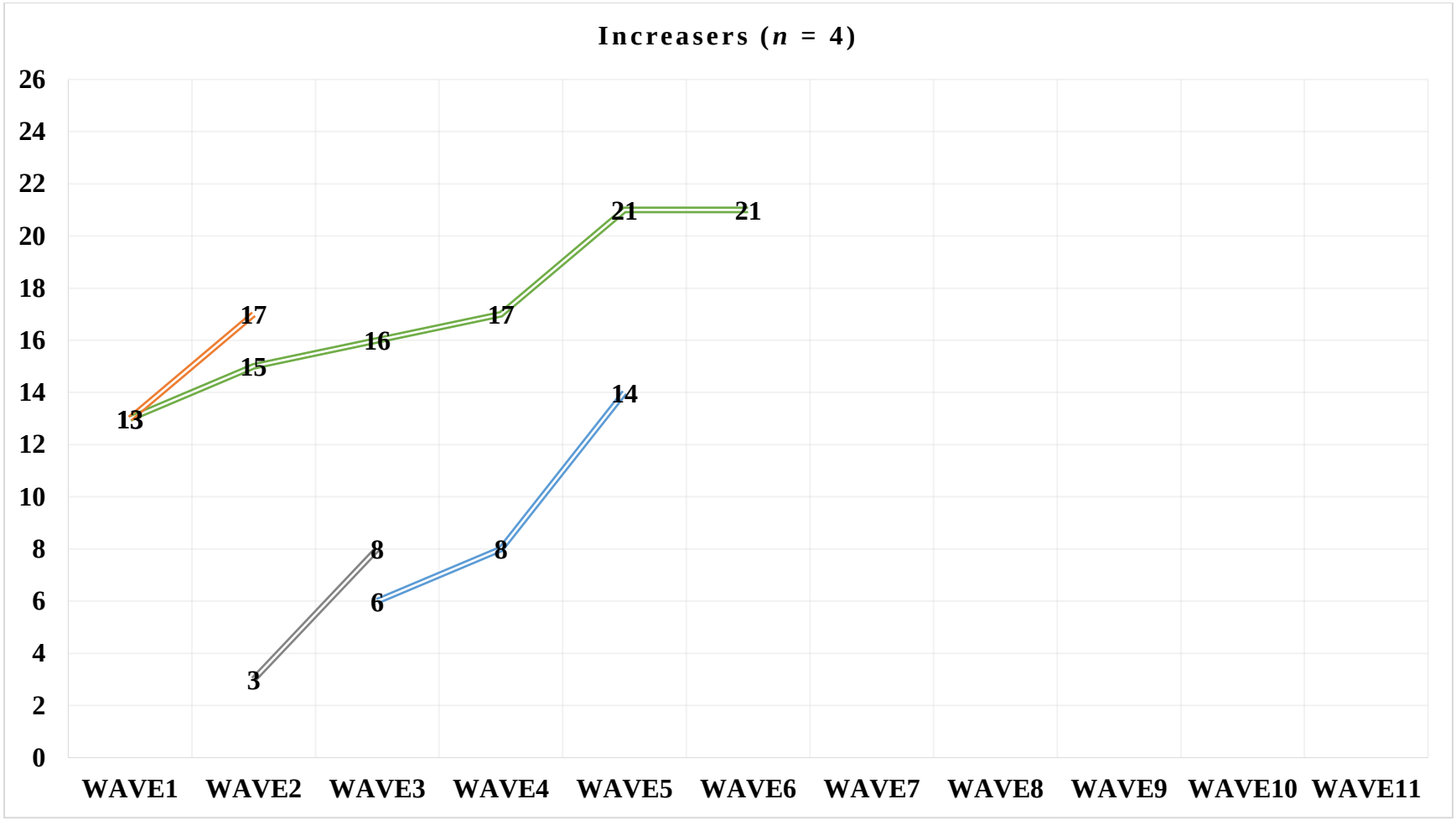
WAVE9
WAVE10
WAVE11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12
10
8
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4
2
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WAVE5
WAVE6
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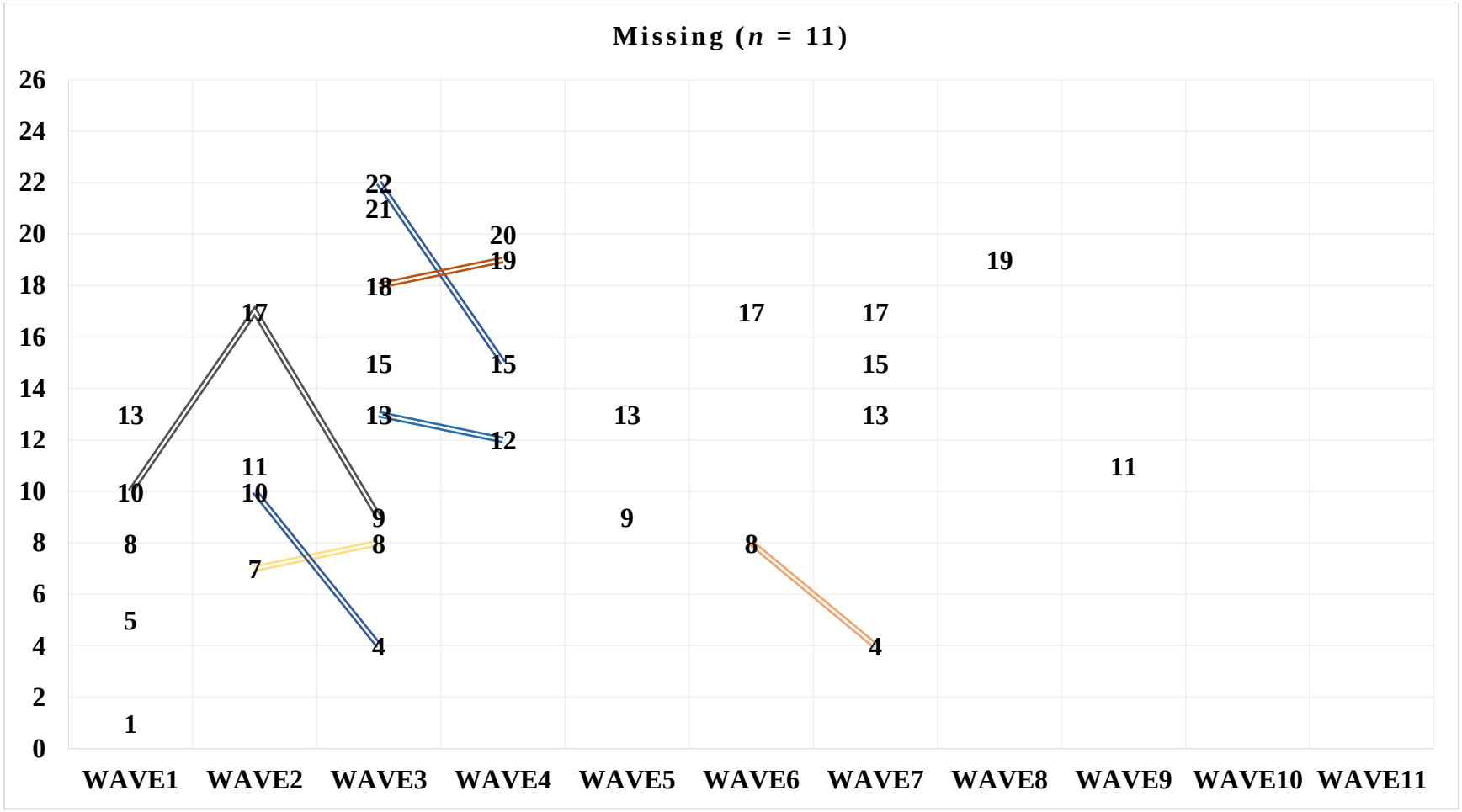
Missing (n = 11)
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20
18
16
14
12
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8
6
4
2
0
WAVE1
WAVE2
WAVE3
WAVE4
WAVE5
WAVE6
WAVE7
WAVE8
WAVE9
WAVE10
WAVE11